

Inspiring Study Day Celebrates 25 Years

“So much information, brilliantly presented” “ The use of a patient story linked all the sessions” “It allowed me to look at the issues differently and re-evaluate..”

2010 marks the 25th anniversary of the West Sussex South Branch. When Jenny Buckley, Head of Education at St Wilfrid's Hospice Chichester heard about this she suggested a 'Celebratory Study Day' involving all the Hospices in the PCT area to recognise 25 years of support by the Association.

The date set, Tuesday January 26th, saw over 90 people arriving at Field Place. Delegates included nurses, doctors, therapists, managers, a paramedic and from the MND Association two RCDAs and AV teams from West and East Sussex

The theme of the day highlighted the complexities of end of life decision making in the 21st century by providing an 'expert commentary' on the legal, ethical, professional and emotional challenges that good and sensitive practice demands.

We were fortunate to have some very experienced experts in their fields to inform us and stimulate our thinking in these areas, and by using a 'real' case study we were able to 'humanise' the theory and relate it to the fields of practice which our audience represented.

Dr. Peter Hargreaves, from the Macmillan Service based in Midhurst chaired the day in his own inimitable style; he even produced news from the day's newspapers which were very relevant to our topics for the day!

We had presentations from Professor Bobby Farsides, Professor of Clinical and Biomedical Ethics at the University of Sussex, Dr. Andrew Thorns, previously Chair of the Ethics Committee of the Palliative Medicine Association, at present Consultant in Palliative Medicine, Pilgrims Hospice, Kent, Dr. Robin Mackenzie, Senior Lecturer, Kent Law School and Kathy White Specialist Respiratory Care Nurse for people living with MND. Each of the speakers helped us think about the implications for people with MND of the end of life care they receive, and informed our own understanding of how we might deliver 'good practice' in the most sensitive way.

We also heard from Dr. Claire Troakes from the Brain Bank who explained how important donations are to help with research, and what was involved if people wished to know more. Finally to give us hope for the future, Dr. Brian Dickie, Director of Research for the MND Association, told us of some exciting research, which brings us nearer, hopefully, to finding the causes of MND and a 'World Free of MND'. Brian always manages in his delivery to make the most complicated concepts understandable. He mentioned research which could possibly stop the motor neurones dying off any further. This, hopefully, could reduce the disability people with MND have to live with. That sounded a very positive 'hope for the future'.

We have so far had some extremely positive feedback. As a branch we are enormously grateful to Jenny Buckley and administrator Lynne at St Wilfrid's for organizing and coordinating this inspiring start to our 25th Anniversary year.

Julia

A surprise presentation to Julia by Alison Moorey
Chief Executive of St Wilfrid's Hospice

Alison gave warmest thanks to Julia and the branch for all the wonderful support they had given people living with MND over the last 25 years. She remembered her first meeting with Kitty and what a source of inspiration the branch & its Visitor Team had been ever since.



WHAT'S BEEN HAPPENING?

AUTUMN QUIZ RAISES £630

Almost 100 people crowded into the Aldingbourne Sports and Community Centre on November 7th for a quiz, created by Erica Burrows, one of our supporters, who has her own unique style of posing questions, ranging from clever to incomprehensible! Teams were of vastly differing sizes, which didn't seem to matter as one of the smaller teams, which included our own Julia Franklin, managed to win first prize! During the interval, fish and chips, supplied by a local fish and chip shop, were enjoyed by all and a raffle, with a large number of generously donated prizes, helped to raise more funds for MND. The Community Centre's own bar added to the enjoyment of the evening and I believe that everyone had a good time. We raised £630 and are grateful to the Community Centre, who waived the fee for the hall, to Erica for making up the quiz and to all the helpers on the night. We hope to repeat a similar quiz evening this year.



GREAT SOUTH RUN SUNDAY OCTOBER 25TH

Congratulations to Team Fisher! £3851 RAISED

Hayley Fisher, daughter in law of Mel stepped into the breach when her husband Simon had to pull out of the Great South Run due to injury. But what a brilliant result for the team of 11 runners: £3406 via Just Giving to N.O. and £445 to the Branch via local sponsorship forms. A VERY BIG THANK YOU TO YOU ALL!



Girls ready to GO

Team Fisher up for the challenge



Hayley, Jason. Race run. Well done!

A PARACHUTE JUMP *The Inside Story*

On 23 September I arrived at 8.0 a.m. at Nether Avon army parachuting base after leaving my house at five in the morning (it was so early my milkman neighbour was still in bed). I was eventually met by my instructor for the jump, Dave, and four other lads who were also going to be jumping that weekend. We were taken into a building dating from the First World War with scaffolding inside to hold it up. During the training we were advised what to do if we went wrong and landed on the roof of the building, which was very fragile. The comment I got when I went to collect my parachute ('...getting a large parachute because of his weight') caused me to wonder whether the building would collapse altogether if I landed on it.

I was advised that if everything went well I would be able to jump that day (Saturday), which sent me into a panic as I had booked a professional photographer to come on Sunday (my Dad!). After a frantic phone call I arranged for them to come down earlier than planned.

During the training an ambulance came rushing into the airfield, blue lights flashing. I found out a little later that one of the beginners on their second jump, despite having the whole of Salisbury Plain to land on, managed to land on a Porsche parked right next door to my parents' car, breaking his pelvis as well as writing off the six-month-old Porsche.

As a result of the accident the jump was delayed to Sunday. Hearing that evening from my parents what had happened made the meal I was enjoying feel somewhat like the Last Supper and I started to feel a little sick at the thought of the next day.

On Sunday morning I arrived at Nether Avon at 8.0 a.m. (hate early mornings) and suited up ready to jump, trying to remember all the information I had learned such as what constitutes a malfunction, when should I use the emergency shunt and would there be time for complimentary drinks on the way down.

We were booked in, waiting for the plane to arrive, when I drew the short straw - I was to be the first to jump (help!). I walked to a perfectly good plane that I was going to jump out of, thinking to myself the New York Marathon would have been a better idea. The plane started to take off. My tummy started to feel funny. Going through my mind was whether I had completed my will, that I wasn't going to see Jenson Button win the F1 Championship and that Keira Knightley could call round and I would miss her.

Then came the call that I had been dreading: 'Into the door, look up and go'. The next minute I was in the air looking up, praying that the chute would open. To my relief it did. I completed the checks and had time to enjoy the silence and look around at

God's great earth. At 1000 feet I turned with the wind and started to think about landing, making sure I was well away from the airfield, the silver Skoda (parents' car) and the silver Ford Focus (mine). At 400 hundred feet I turned into the wind and started to prepare to land, pulling the toggles a little too early so the landing was a bit harder than planned but I was fine. I kissed the ground for good measure.

MARTIN R.



£600 RAISED FOR RESEARCH

SANTA CLAUS RUN RAISES £300

"They were very wet beforehand" said proud grandma Betty "but managed the run in the dry. "

Natalie and Chris, Betty Poole's grandchildren ran in the Annual Santa Run at Greenwich on December 6th. They ran in memory of their much loved grandfather and raised £300 for the *Eric Poole Tribute Fund* which they have set up in his name. Natalie hopes to run again next year.



For information about tribute funds do visit the MND Association website www.mndassociation.org and enter tribute funds in the search box

HOLMBUSH CHRISTMAS COLLECTION

Once again the "Worthingaires" kindly put their musical skills on display and sang for us at the Holmbush shopping centre in Shoreham on the Sunday before Christmas.



In spite of the very cold weather and the reduced number of shoppers due to the credit crunch, the choir attracted enough attention to encourage the public to donate generously and we managed to raise over £250 for MND.

Our warmest thanks go to all the members of the choir, the collectors and the Holmbush Centre for their support.

CHICHESTER FUNDRAISING AFTERNOON RAISES £620

Jean H, whose daughter Sue had had MND, organised with the help of her friends, a great fundraising afternoon for us at her home in Chichester on November 21st.

It was a lovely afternoon with lots of stalls including one manned by Rosemary, selling MND Christmas cards, and home made Christmas puddings. All this plus a super raffle... and the grand total raised was a superb £620!

Very many thanks to Jean and everyone involved.

WHISKERS & TALES

We were delighted to welcome back Doreen Taylor for a second visit to our October Branch Meeting. From the first slide we were immediately transported from the chill of a dark evening in Sussex to the wide open spaces of Africa.

Doreen explained some of the technical problems photographing wildlife under different conditions and in various light. She and her husband have clearly developed a wonderful relationship of admiration and respect for the animals they photograph - especially their favourite elephants.

Her last slide, amusing and poignant was of an elephant nonchalantly taking command of a road - traffic keeping a respectful distance. Seeing this shot caused us all to reflect on who the land truly belonged to.

The Supply of Rilutek

WE are continuing our efforts to find a solution to the current problems with the supply of Rilutek (also known as riluzole), in partnership with everyone in the supply chain.

A second round-table meeting was held on 14 October with: • Alliance Healthcare • The Association of the British Pharmaceutical Industry • The British Association of Pharmaceutical Wholesalers • The Pharmaceutical Services Negotiating Committee • Sanofi Aventis and The Department of Health. All parties reaffirmed their commitment to ensuring that all people with MND are able to access Rilutek easily and reliably.

The problem has proved extremely difficult to address: it arises from the pound's weakness against the euro and higher drug prices in some other EU member states, which make it profitable to export Rilutek from the UK. Given the rapidly progressing nature of MND, and Rilutek's position as the only effective drug in slowing the progression of MND, the fact that a simple solution cannot be quickly found was agreed by all parties to be deeply frustrating and troubling. Nonetheless, serious consideration is being given to a range of possible routes to a resolution. Discussions between all the parties who attended the meeting were to continue for the rest of 2009, and it is hoped that a workable solution will be available in 2010. In the meantime, the Sanofi Aventis emergency arrangements remain in place: people with MND who cannot obtain Rilutek can ask their pharmacist to arrange for a **supply to be sent direct by phoning 0800 854430.**

There have been reports of pharmacists being reluctant to use this facility because, for instance, they fear they might lose the discount they receive from a wholesaler. We have been assured this will not be the case, and pharmacists can contact either Sanofi Aventis (as above) or the Pharmaceutical Services Negotiating Committee (01296 432823) if in doubt. Thanks to all involved for their willingness to participate and dedication to finding a way to secure the supply of Rilutek for people with MND.

PhD project findings

IN OCTOBER last year, Gabor Morotz started his PhD in MND research in Professor Chris Miller's lab at the Institute of Psychiatry, King's College in London.

His project is funded by the Association and we have recently received the first year progress report. As is traditional, the first year of Gabor's PhD was a time for learning the techniques that will set the groundwork for the studies to come. The non technical summary of their report is reproduced below:

Background to the project: Motor neurons comprise cell bodies and processes that extend from them called axons and dendrites. The axons connect to muscle cells to facilitate muscle contraction. Most of the proteins present in the cell are synthesised in the cell body at one end and are then carried into the axon by a process termed "axonal transport". We now know that this process goes wrong in motor neuron disease (MND) and also that it is one of the earliest (and possibly *the* earliest) defect. This means that damage to axonal transport is an important part of the disease process. What we do not know, is quite how axonal transport becomes damaged. Thus, if one considers axonal transport to be like a train journey from London to Edinburgh, there are a number of ways in which the journey can be disrupted. Firstly, the engine may be broken; secondly, the engine may be fine but there may be no fuel for it; thirdly the rails may be broken; fourthly, the signalling systems may be damaged and lastly, there may be damage to the carriages so that they cannot connect to the engine.

Some, rare forms of MND are inherited and we have shown that mutant superoxide dismutase-I (SOD1) that causes one of these inherited (familial) forms of MND damages axonal transport of 'mitochondria', mitochondria are the energy sources of the cell. Recently, we have found that another mutant protein that causes a familial form of MND also damages axonal transport. This protein is called VAPB. The aims of this project is to analyse how mutant VAPB damages transport.

Progress so far We have found that mutant VAPB damages axonal transport of mitochondria in a highly similar fashion to mutant SOD1. The damage is specific to one direction (anterograde but not retrograde) which is akin to damage to forward but not reverse movement in a train. We are excited by this finding as it indicates that two different MND toxic insults work in similar ways.

We are now analysing the mechanisms that might cause this effect and have so far found that mutant VAPB does not appear to grossly affect the attachment of mitochondria to their forward "engines" (kinesin). However, we have found that the mutant VAPB is more closely associated with mitochondria than wild-type VAPB.

A VERY BIG THANK YOU to DAVID BUNDELL who has stepped down at the end of 2009 from his longstanding role running the Thumbs Up Club. And a warm welcome to GRAHAM SMITH who has taken up the baton



THUMBS UP CLUB Winners:

OCTOBER

1st 87
2nd 32
3rd 109

NOVEMBER

1st 39
2nd 32
3rd 33

DECEMBER

1st 28
2nd 92
3rd 90
4th 72

Don't forget to join up now for 2010. For a £12 annual stake you have 12 chances to win. Contact Graham on 01403 700286 or email him at info@littleghyll.co.uk for further details

AUSTRALIA BY WHEELCHAIR

When my partner, Terry was diagnosed with MND three years ago, we determined to make the most of the time he had left and to travel as widely as we could for as long as we could. In October 2007 we took a coach trip around New Zealand and were overwhelmed by the kindness of our fellow Australian travellers who fell over themselves trying to help Terry, who was, at this time, on crutches. We came home with several invitations to visit Australia, which we gladly accepted and so, in April 2008, we flew to



Melbourne, complete with wheelchair, 2 cases, crutches and bags.

Anyone who has ever flown with a wheelchair will know how easy it is and what wonderful treatment you receive. We flew with Singapore Airlines and thoroughly enjoyed always being first on the plane,

having a private "pusher" (although I found I usually had to run to keep up with them) and being able to use the special needs lounge at Singapore Airport, with TV, free tea and coffee and even a massage chair, which was reluctant to release your legs at the end of an energetic massage!

We arrived at Melbourne at 6 o'clock in the morning and there, waiting, were our good friends, Bill and Bev, who had risen at dawn to drive 2 hours to collect us. They lived in a single

story wooden building way out in the country, with kangaroos and a wonderful assortment of birds in the garden and a gold mining stream down the road. Bill was determined that Terry should



experience as much as possible and, not only took us to an old gold mining town and a drive along the Great Ocean Road to see the famous Twelve Apostle rocks, but also took Terry sailing on his catamaran on a lake, let him drive his lawn-mowing tractor and carried him into the stream to do some panning for gold, sadly without success!

The next part of our trip involved flying to Sydney, from where we took a train up to the Central Coast to stay with another friend, Viv. The most challenging part of travelling was using the trains but, here again, the Australians were always willing to help. The wheelchair was carefully stacked with Terry (obviously), one suitcase between his legs and one across his lap, 3 bags attached to the handles and crutches balanced on the footplates. The slightest lack of balance meant that the whole bundle tipped over, which wasn't very pleasant for Terry! My method on arriving at a station was to stand in the middle of the entrance, with the wheelchair, looking totally helpless (not difficult) when someone would always come up and ask to help.



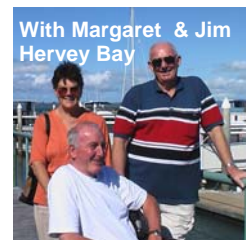
We would then be guided to the lifts to the right platform and told where to position ourselves in order to make use of the ramp, which would miraculously appear when the train arrived. There was also always help stacking and carrying all the luggage.

Holidays long and short

We spent a wonderful 3 days with them seeing all the sights of Sydney, although the weather was disappointing and rained a few times. We stayed in a hotel with a very dodgy lift, which made life a little difficult, but enjoyed our stay in spite of that.

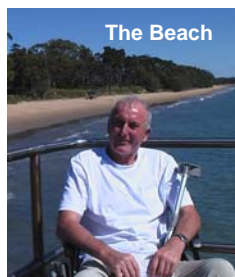
Our final trip was a flight up to Hervey Bay in Queensland, where we stayed with another wonderful couple, Jim and Margaret, who again made us very welcome in their lovely bungalow on a specially designed estate for retired people, complete with swimming pools, communal barbecues, community hall, library, gardeners, nursing home, transport and all sorts of activities. By a great coincidence, their neighbour, a very lively and talkative English chap, also had MND, so he and Terry had a lot to talk about. There was no local group like ours and we felt that the services for people with MND were not as good as ours.

The weather here was much warmer, with beautiful sunshine for the whole of our 2 week stay. Jim and Margaret would take us down to the beautiful beach, where I could push the wheelchair along the path under shady trees for miles. We went on a boat trip on a boat that was owned by a disabled woman and was completely wheelchair adapted and even managed to get Terry swimming in the sea by walking in with crutches.



At the end of our stay we took yet another train down to Brisbane, where we were met by another couple, whom we had also met in New Zealand, who took us back to their house for dinner before we took the final train to the airport for our flight home.

What wonderful friends we had made through their willingness to help someone in a wheelchair! To anyone who is wondering if they can manage a journey, I can only say "Give it a go!" You will be amazed at the kindness of most people. Terry sadly lost his battle with MND in February 2009, but how he enjoyed those holidays and what wonderful memories I have left.



Sue K

AND MUCH CLOSER TO HOME.....

Peter C writes:

My wife and I took a short break to Bournemouth recently with *Roadmark Tours* and stayed at the Marriot Hotel.

Members with MND may be interested to know that the staff were very helpful at all times both on the coach and at the hotel.

When we arrived our room was promptly changed to one with a large bathroom with disabled facilities. It was reassuring to receive such kindly assistance and we would thoroughly recommend this enjoyable 3 day tour.

NOTICE BOARD

RAFFLE PRIZES ALWAYS NEEDED

For events and branch meetings
Please contact any committee member

THANK YOU!

FUNDRAISING IDEAS

We're always on the lookout for new, exciting or different ideas for fund raising. If there's an event or a scheme that you think would be worth a try, please let anyone on the committee know.

SPEAKERS

If you know a good speaker who would come along to a branch meeting please have a word with one of the committee members.

If you would like to be involved in arranging a demonstration or entertainment at one of our branch meetings, again please just speak to any committee member.

YOUR NEWSLETTER

If you would like to be involved in the production of this newsletter or would like to become the Editor please contact Helen at RHCJ@aol.com

DO YOU WRITE?

Articles are always required for forthcoming editions of the Branch Newsletter. Please submit any news, stories, poems, competitions, views or information for inclusion in the next edition to any committee member or direct to Helen, Email: RHCJ@aol.com

DATES FOR YOUR DIARY

YOUR HELP AND SUPPORT IS VERY MUCH APPRECIATED

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.

- FRIDAY February 19th** **A February Fanfare**
The Woodlands Centre Rustington 7.30
Concert with young performers organised by Littlehampton Ladies' Inner Wheel Tickets £8
- MONDAY FEBRUARY 22nd** **Branch Meeting The Laurels 7.30**
Social with Shuffleboard
- MONDAY MARCH 22nd** **Branch Meeting The Laurels 7.30**
Laura Burdon – 20th C Fashions in Furniture
Laura collects old tools for a charity which sends them to the 3rd world after refurbishment. Please bring along any you have. Can include knitting needles as well as chisels etc! Collection of larger items can be arranged.
- MONDAY APRIL 26th** **AGM - Buffet - Presentations The Laurels**
- SUNDAY April 18th** **SPRING CONFERENCE Dartford**
Transport available to this excellent day
Free to people living with MND & their carer
- SATURDAY June 19th** **MND ROCKS**
Rock Concert at Worthing Rugby Club
Visit www.mndrocks.com for more details
- TUESDAY July 6th** **COBNOR CHAIRBOAT 11.00 am**
Trip round the harbour. Bring a picnic
- SUNDAY July 25th** **STRAWBERRY TEA WITH JAZZ**
Westbourne House School
- TUESDAY August 3rd** **COBNOR CHAIRBOAT 2 11.0am**
- 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: <http://www.mndassociation.org>
MND Association Reg. Charity No 294354

WEST SUSSEX SOUTH

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