

**Reading and
West Berkshire
Branch**

www.mndrdgwberks.freeuk.com

In this issue	
Treasurer's Report and Farewell	2
Patients Like Me	2
Family Golden Wedding Fundraiser	3
Summer Concert	3
Profile on Colin	4
Gill's Open Day	4
Forthcoming Events	4



**Mon
20th
August***

Reading Canoe Club
The Warren, Caversham

2.30pm-4.30pm.

Parking Limited/
Wheelchair priority access
For details, contact Val on
0118 9789063

*Please note this is a change of date from previously advertised

FLOODS NO BARRIER FOR ANNE!

The Nation may be gripped in flood fever, but Anne Smith, PLwMND, has her own story to tell. Venturing out on "Flood Day" - Friday 20th July—was not for the faint-hearted and Anne is certainly not that!

Over 12 hours, and strapped in her wheel chair, Anne recalls her hair-raising journey from her home in Mortimer to the Charles Clore unit in Thatcham—and back again—and again!:



"Friday is the day I go to the Charles Clore Day Centre. The rain was appalling and I thought, 'no day centre for me', but I knew Irene the volunteer driver wouldn't let me down. She was saturated but cheerful as ever as she loaded me in the transport.

As we arrived at the A4 road, it was just like a river, but, although the going was very slow we arrived safely in Thatcham. Irene took the ring road and then the car had no electrics and the windscreen wipers wouldn't work, but Irene battled on. The rain was so bad we had to stop. Irene summoned assistance from Charles Clore and they in turn got a taxi to pick us up.

The taxi driver was a tiny lady and saturated but she loaded me into the taxi. I was not secured in any way - for some reason I wasn't able to be strapped in. Each way we went the roads were too deep in

water, so the taxi mounted the pavement and that's how we got to the day centre - 2 hours for a journey which normally takes half an hour!

It was suggested that I stay the night at the hospital, but that wasn't an option for me. My husband was called to see if he could help, I knew he would. Somehow he got through the floods and we left the hospital - I needed to get home to Mortimer as I had no clothes, I needed feed and pump as I have a peg and medication.

We went via Brimpton and Tadley, and, although it was a long journey, we arrived at Mortimer safely. As I spend my weekends at the family home we then set out again for Thatcham! My husband decided to go back a different way, it was a nightmare. Woolhampton was closed to all traffic, we had to turn round and try the M4. On the M4 there was a landslide, we had to crawl along. Newbury was like a river, but we arrived in Thatcham at 9.30pm. As we drove down Pipersway, there were 100's of cars parked on the verges. The entrance to our road was 2 feet deep in water, but my husband drove through it. We were home at last!"

Contributed by Anne Smith and Joanna Knott

Braving the depths -

Piper's Lane, Thatcham - close to Anne's family home.



The conditions on Friday 20th July

(Photo by M Bardsley-courtesy of Newbury Weekly News)

TREASURER'S REPORT AND FAREWELL

We said farewell recently to our Treasurer, Barry Clouting, who retired after 4 years' dedicated service to the Branch. Here his wife Carolyn, who is a nurse, writes about how Barry was inspired to help people living with MND:

"Barry had never heard of motor neurone disease until my best friend Anne was diagnosed with it in 1995. Anne did not live locally and never felt she wanted to mix with other people living with motor neurone disease so Barry & I spent at least one day a week with her for the duration of her illness. After Anne's death in 2000 there was a huge hole for both, and a certain restlessness in Barry to do something for Anne – he already did some voluntary and charity work but Anne's plight haunted him.

I asked Downe House school, where I work, to adopt MND as their yearly charity which they did and had an extremely successful year raising funds. When the Headmistress received an invitation to the "supporters" lunch she asked Barry and I to attend and take 2 girl 'fund raisers' with them. Barry sat on Anne Halifax's table – need I say any more!!!! Once Anne Halifax mentioned they were looking for a new treasurer Barry could see that this was his way of helping Anne indirectly, as she always thought of others before herself and would have wanted as much done for others as possible.



Barry Clouting, receives a vote of thanks from Branch Chair, Margaret Moss, at the recent AGM

When the Branch MND books have not quite balanced and he has poured over each entry to find the problem he has only had to think back to the visits to Anne to make him grit his teeth and persevere until the error was discovered!

Barry has felt greatly privileged to be part of such a caring, active, supportive Branch not only in their care of people living with MND and their family and carers, but also of each other. He will hugely miss his involvement, the camaraderie of the committee and the time spent in the company of very special people – those living with MND. He has gained enormously from his involvement with the Branch & it has helped him feel he has done his bit for Anne – like so many people living with MND, Anne was a very special person who was an inspiration to all who came into contact with her. Barry and I are retiring to Poole to be near our 2 grandsons and their boat but will remember our connections with the Branch with great affection and will look forward to meeting up with some of you at the Annual conferences and meetings."

Contributed by Carolyn Clouting

And here are some extracts from Barry's report on the Branch accounts for year ended 31st January, 2007:

"Another good year with total income dropping back slightly, after the initiatives of recent years to build up funds for the Neurological Nurse project, coupled with fewer requests for care and support of PLwMND.

The very positive help provided by Carol Allen, the specialist Neurological Nurse, has fully justified our 50% contribution to the £90,000 contract. All the restricted funding received has been used in the £25,256 expenditure up to the 31st January 2007, and a further £20,000 of 'committed funds' is allocated in the current year to complete the contract.

The support given for the work of the Branch in donations and from fund raising activities is extremely generous and re-assuring. Without the regular input of your financial support the Branch could not work effectively.

In expenditure, Administration (8% of total), again reflects the significant cost of stationery (56%) including colour printing the Newsletter. It is vital to keep a high profile for the disease in the region, so eye-catching Newsletters are an essential element to fundraising.

And, remember, if you pay UK Income Tax/Capital Gains Tax and make a Gift Aid Declaration, we can reclaim 28p for every £1 you donate until 1st April 2008 (Sadly, it then reduces to 25p).

I am particularly grateful to everybody who has contributed throughout my period as Treasurer thus making the job rewarding and enjoyable.

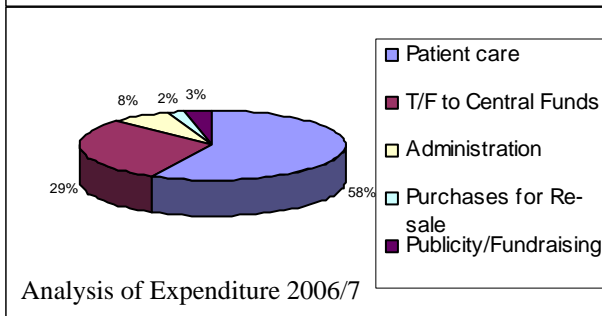
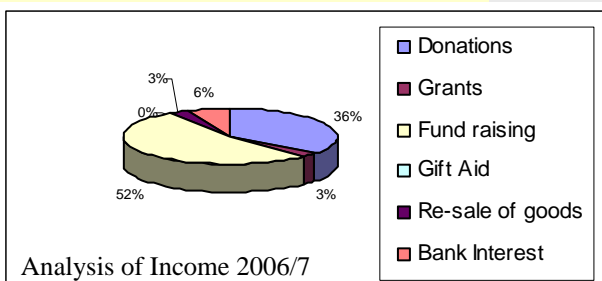
Contributed by Barry Clouting

The branch is fortunate in having Ed Gryglaszewski as its new treasurer. Ed can be contacted at 27 Ashton Road, Wokingham, RG41 1HL or on 0118 9789069 – we welcome him to the team and look forward to working with him.

WHERE THE MONEY GOES

Total Income for 2006/7 was £38,579 and total expenditure £39,752, which includes £25,256 to the Neurological Nurse Contract. Funds therefore show a deficit of £1,174.

Accumulated Funds (at 31st January 2007) were £61,764.07, with £20,000 'committed' for the Neurological Nurse appointment in West Berkshire



Patients Like Me *by Roland Lewis*

"I was introduced to the www.patientslikeme.com web site by Dr Paul Wicks who is part of the research team at PatientsLikeMe. It was started in 2004 in the USA as a tool for helping plwMND, otherwise known as People with ALS (PALS), to manage the disease. It enables you to monitor your long-term progress, your treatment regimen, and your associated symptoms.

You can also use PatientsLikeMe to find other patients in your condition and learn from their experiences. By monitoring your progress and learning from other patients, you can improve the way you manage your disease.

PatientsLikeMe is expanding all the time and now caters for Multiple Sclerosis and Parkinson's disease. Currently, there are 1271 PALS registered on the site from all around the world along with carers (CALS), guests and support staff such as Paul. 66 new PALS registered in July 2007 and 60 PALS are from the UK.

The power of having a community of "patients like me" was demonstrated recently when a user's weight dropped precipitously, which can accelerate a patient's deterioration in ALS. Because patients track and share their important outcome measures, another patient was able to remind him of the importance of keeping his weight up.

Another benefit of PatientsLikeMe is that it can very quickly produce meaningful results from research surveys. In May, Paul published a questionnaire and 279 PALS and 87 CALS responded in a week, which is something of a record in ALS research.

I have only been using PatientsLikeMe for a few months but I have found that it has made me think more about my illness and to compare my symptoms with other people. For example, my hands get cold very easily but only 10 PatientsLikeMe have reported this. My next step could be to see what they have done to alleviate this symptom.

Paul also moderates www.build-uk.net which is a UK web site with 435 members with an interest in MND. Members post messages/questions to forums and discuss the replies."



www.patientslikeme.com

Newsletter Editor, Mary Watson, proudly displays the 5 Year Long Service Awards, which were presented recently by Margaret Moss.

Mary comments, " I feel so privileged to be part of the Newsletter Team, and hope that we continue to get the message right for contributors and readers. "



Family Golden Wedding Fundraiser *by Janet Hankin*



Janet sent us this photograph of her parents, Mr and Mrs Hankin, at the occasion of their Golden Wedding Anniversary in July this year, along with cheques totalling £150, which were collected from the small group of family members who were present to celebrate the day.



Janet writes:

" This is in memory of my brother Alan, who died last year....be positive of my continued support for your branch."

Many thanks to Janet and her family for their generosity and continued support of the Branch.

Summer Concert *by Val Pearson*



The 55-strong Cromwell Singers, Newbury's oldest amateur choir, gave a concert on Saturday, June 23, at the town's Methodist Church in Northbrook Street during MND Awareness Week, raising £374.

My sister, Maureen and I, were among the audience who were entertained by a medley of songs displaying different styles, from the serious to the flippant. It brought back memories of my childhood at school, with offerings from old English folk songs and madrigals. The programme also featured music from popular stage shows such as Beauty and the Beast and The Phantom of the Opera.

Our thanks go to all the choir for their generous support, but, in particular, our thanks go to two very active members of the choir, Ann Minks, who lost her husband Bryan to motor neurone disease eight years ago and concert organiser, Gwenda Hutchinson. Gwenda and her husband, John, are long-term supporters of the branch. John regularly helps to raise money for us by organising collecting boxes in Great Shefford.

(Our picture shows Val –far left—with cast and audience)

Profile on Colin Moss

Colin, 56 , writes about himself , his interests and his recent work for the Branch and MND Association:

My interest in the MND Association came about in January 2002 when I was diagnosed with MND (ALS). In fact I have been lucky in that my decline has been relatively slow and I am still (just) ambulant. I have now retired for health reasons after working for Panasonic in Thatcham for 15 years as a Mechanical Design Engineer until 2005. This Job gave me the opportunity to visit Japan many times, and also China and Hong Kong.

I was a keen footballer playing for Swindon Town at schoolboy and youth level and Wiltshire at youth and senior level. I played for Chippenham for 12 years until I was 38 , when I was made a life member of the club for services rendered, and I also enjoyed many other sports.



My other main interest is classic cars and I own two at present. Luckily I am still able to drive, although cleaning them is now becoming a bit of a marathon, as is cutting the lawn.

I was invited onto the local branch committee and had little hesitation in accepting. The committee and other volunteers who help to make the Reading and West Berks branch one of the strongest in the country have inspired me to help others . Since I realised my health was holding up quite well I have tried to help out more within the branch with fundraising, etc. Recently along with a few others I was also able to help raise awareness of MND by being interviewed on ITV Thames Valley Tonight and also BBC Radio Berkshire (live) along with Jane Gilbert who was the driving force behind the publicity push. The subject was the potential link between MND and football. Although my speech is now starting to be affected along with some difficulty with emotional control I survived the experience, learned from my mistakes and actually quite enjoyed it.

Recently I completed my training to become an MND Assoc. Volunteer Visitor so I can befriend and support others diagnosed with MND. I am hoping the fact I am still reasonably active 5 years after my diagnosis will give them a lift as it a shock (to say the least) when you are told you have MND and 50% die within 14 months.

I am planning to move back to the Swindon area in a few months to be nearer my family but hope to keep in contact with the branch and still intend to attend drop-ins occasionally.

Contributed by Colin Moss

Forthcoming Events

Summer Tea Party

Canoe Club, Reading

Mon

20th August*
2.30- 4.30pm

*Please note change of date

Drop-in Meetings

Venue TBA

Thurs

13th September
6.30-9pm

Metal Detecting Rally

Englefield Estate

Sun

9th September

National AGM

Hilton Metropole, Birmingham

15th/16th

September

Gill's Open Day

Gill Cheetham, and her long-term gardening friend Andrew, were brave enough to open their gardens in Bracknell this year under the NGS Yellow Book Open Gardens scheme.

After a morning of rain on 1 July, the gods were kind and the sun shone. Visitors were so grateful for a glimpse of sun after a week of rain, they came out in droves to admire the subtle perfumes and beautiful flowers. The garden looked stunning and I can only admire someone who must commit so much of their lives to keeping a small corner of Berkshire looking so beautiful. For the weak-willed amongst us, coffee was served, with scones piled high with cream and a wicked chocolate cake. Gill donated money raised by these treats to Branch funds.

Contributed by Val Pearson



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FIGHTING MOTOR NEURONE DISEASE