About 35 people attended our AGM at the Holiday Inn in Oxford this year including several people with MND. More people came than last year but we always hope to see you all. Again we had excellent speakers and enjoyed a sandwich lunch.

During the business meeting Acting Chairman John Kay gave a piece about all our activities in the last year. He was thanked for standing in during the last two years. John welcomed our new Chairman David Cairns. Gemma Richards our new Treasurer gave a report on our finances. Marilyn Hamblin was thanked for keeping an eye on things until we were able to appoint Gemma. We have a healthy bank balance and are able to send a substantial amount from our branch funds to National Office this year.

After lunch arranged by the committee we listened to the following speakers.

**Professor Colin Blakemore** our President who was featured in a recent article in The Times. He was able to give up to date information about research and answer questions.

**Dr Kirstine Knox** Chief Executive of the Motor Neurone Disease Association who discussed the impact that certain sections of the Human Fertilisation and Embryology could have on the search for effective treatments for MND.

**Dr Kevin Talbot** Neurologist from the MND care centre. Gave an update and mentioned the Branch’s contribution to the non invasive ventilation programme. They now have a specialised nurse to advise on breathing problems.

Thank you to all our speakers for taking time to come and talk to us at the AGM.
**Family and Friends Group**

The last two meetings of the **Family and Friends group** have set record attendance numbers which shows how popular the group now is. Twenty seven people came along to our November meeting entitled Wheels. Jenny Rolfe, OT from the Oxford Centre for Enablement explained how wheel chairs could be provided for people with MND from a special service operated by the MND Care Centre. It was important that wheel chairs were carefully suited to the requirements of each person. Ideas were shared on the subject of travelling by car. It was good to see several members of the South Bucks group at this meeting.

Ann Mills spoke about the benefits of Therapeutic Touch at the meeting in February, and recounted her experiences of treating people with this therapy. She made the point that anyone can be taught to apply it with practice.

For a change the next meeting will be at **Worton Park, Cassington, near Yarn-ton on Wednesday 21st May** – a mainly social meeting when we be exchanging ideas, hints and tips that could be useful. Directions and a map will be available. Contact Lesley Ogden for details on 01235 850372.

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**SPONSORED WALK SATURDAY 6TH SEPTEMBER 2008 11.00 am**

I don’t give up easily……last year we cancelled because of lack of interest but some determined people still did a sponsored walk and we raised about £600. So.. I have contacted the Duke of Marlborough and he has given his permission for us to hold our sponsored walk in and around Blenheim Park. Details to follow later in the year.

Jackie Reeves, Bruce Howard

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**TECHNOLOGY**

It would help us a lot if you gave us your E mail address. We only have E mail addresses for about 25 of the 180 on our mailing list. We should now be able to send the newsletter electronically saving postage. We can also contact you quickly. We would like to have a readers letters page, but nobody has sent anything! We want to know what you think. Please send your comments, letters and photos.

We still have no one to set up a website for the Oxfordshire Branch, can you help us??

For all of the above contact:

Jackie Reeves
Branch Secretary/Newsletter Editor
jackie.reeves@which.net
01993 868768
OUR NEW CHAIRMAN

We are really glad to have found a new Chairman through REACH - here is what he says about himself!

DAVID CAIRNS

I am married with two daughters aged 22 and 24. I was born and grew up in Northern Ireland, one of 7 children. Later I graduated from Queens University Belfast with a BSc in Mechanical Engineering.

Work History
I joined a leading Oilfield Services company called Schlumberger and worked for them providing Technical Services to oil companies. During my 15 years with them I worked in Qatar, Kuwait, Pakistan, Dubai, Saudi Arabia, Oman, Aberdeen, Great Yarmouth and Paris.

We decided to return home to the UK to give our daughters a permanent place to grow up in and to give them a good education. I joined a Security Company providing Manned Guarding Services across the UK. I then worked for another 14 years in the industry at Board Level including being Managing Director of a company employing approximately 4000 people.

Why do I want to do some voluntary work?

I retired two years ago. Having done all the things that needed to be done to the house etc, I decided that perhaps I had a lot of “work experience & skills” that might be valuable to some organisations. I was put in touch with an organisation called REACH which specialises in putting volunteers with business skills in touch with Charities that may benefit from those skills.

I know very little about MND and was apprehensive about meeting your committee as I was unsure how best I could help or how my skills would benefit the group. They have assured me that I could be a valuable member of the team.

What can I offer?

Enthusiasm, leadership, organisation and management skills. I would hope that I can bring focus to the group and help it to achieve its’ goals of supporting those with MND and raising general awareness of the disease.

CHARLBURY JAZZ EVENING

The Oxford Classic Jazz Band seems to have a fan club in Charlbury and among the MND Association. They played to a capacity audience on 24th November in the Memorial Hall and, despite their youth, played with experience and style. This year Thomas “Spats” Langham was with them. He is always a delight with his versatile playing of banjo and guitar, and his vocals in the style of Al Bowley.

Suppers of all shapes and sizes, some elegant and grand, were consumed while the ale and wine flowed. Once again thanks to “Ye Olde Three Horseshoes” for providing the bar. Thanks too to everyone who contributed to the raffle.

Someone told us that this, the eighth, was our best ever Jazz Evening. I think we would agree. We raised £653.33 for the Oxfordshire Branch.

John and Stella Waterer.
It is with sadness that we report the death of our committee member with MND Phil Baker. Phil and his wife Jan responded to his illness with dignity, practicality and humour. Phil had the support of a loving family and was always keen to be involved in branch activities. He became increasingly interested in (and frustrated with) the provision of facilities and equipment for people with disabilities. Phil was unstinting in giving help when asked for advice on cars and vehicles to take wheelchairs. He had long connections with the motor industry and drew on his specialist knowledge. We shall miss him on the committee. Our thoughts are with Jan and his family.

NEW YEARS PARTY
SATURDAY JANUARY 19TH 2008

This year we had our Annual New Years Party at “The Bell” in Charlbury. This proved a popular venue and several people attended. We were able to arrange wheelchair transport so that two of our members could attend. After a sandwich lunch we had a talk from Liz Bellido the Physio involved with the MND clinic. The Branch was able to fund part of her costs so that she could attend the International MND symposium in Toronto in December 2007. She found the symposium very useful as well as having a good time with her colleagues. The session ended with a lively discussion about the problems of living with MND. Thank you to committee members who arranged the day.

The Oxfordshire Befriending Network

The Oxfordshire Befriending Network provides befriending, advocacy and counselling to people with life threatening or terminal diagnosis. Their services are available across Oxfordshire and are provided free by fully trained volunteers. I have been befriended by a volunteer for the past 3 yrs. My volunteer befriender visits each week for 2/3 hrs, to provide emotional support, just listen or help in a practical way. I enjoy having a befriender and I value her support hugely. In the past, I have also used the advocacy and counselling services. If you or someone you know would benefit from their support Telephone: Linda Ridgway or Ally Stott on 01865 791781 or email: enquiries@oxonbefriending.net

Moira McIver

Leanne and Sarah

Albert Connor’s daughter Leanne and grand daughter Sarah collected for MND in Morrisons in Banbury. Thank you for your hard work!
For some reason a vicar with MND - which is what I am - is a minor news story. It was a chance comment of a church member that led to my being interviewed for The Door, the Anglican newspaper serving Oxfordshire, Berkshire and Buckinghamshire. To be more accurate, my wife, Jane, and myself were interviewed for the ‘God in the life of...’ feature in January, by an excellent journalist, Rebecca Paveley. Her aim was to let us speak and she succeeded (with one minor inaccuracy - which was not bad for a full page spread!). My fear was that it would make me sound like a celebrity or a saint - both of which are far from the truth. Everyone with MND will know the frustrations (there must be a better word to describe daily grinding and frustrations which are part and parcel of the disease) and its unremitting juggernaut frightening inevitability. Well, I’m not immune. I hate the beast. One part of the article which elicited most response was talking about dying, which I admit I don’t look forward to - even though I do believe in a better afterlife. But that doesn’t help dealing with the present, does it? I suppose the ‘God in the life of’ bit was best summed up by the discovery that as I get more and more useless, I become no less valuable to God. That’s something I’ve discovered from people who surround me, in the church, the village and my family, who seem to love me nonetheless.

Next BBC Radio Oxford contacted me. They’d seen the article. Would we be interviewed for the Sunday night programme Journeys? So Mike Beau-mont came to see us in our home in Stanford-in-the-Vale. After the inter-view, he warned me that my voice might be a problem, so would I mind if it was dubbed or summarized? In the event it was dubbed by an actor. And when I tuned in to the broadcast, I could see why. Jane’s voice was clear as usual, but was that how I really sound? It was sobering how much worse my voice sounds outside my head! How does anyone bear listening to me when I’m taking a service or, worse, preaching? Again the broadcast produced feedback, including from others in our sort of situation. The catch question of this interview was, ‘You’re a Christian. Why do you think God allows something like this to happen to you?’ My answer was the same as Roy Castle’s about his cancer, ‘Why not me?’ I don’t believe God insulates us against the harsh realities of life, but I’ve found He’s still there with me through it all - and that helps.

This media business must be addictive, as I’ve now written a book, My Don-keybody, which is coming out in October, published by Monarch. It’s about having a stubborn ass of a body which is steadfastly going on strike. I hope it will help people understand more about this diabolical MND and how precious life still is. Please do contact me if you would like to talk or comment on this article.

Michael Wenham
01367 710267
wenhams@xalt.co.uk

Preheat your oven to 175C. Generously butter a loaf pan. In a medium mixing bowl beat the egg. Add the breadcrumbs, lemon juice, mustard, cayenne, tumeric, melted butter, sage and salt. Add to the salmon and onions and mix very well. Press in to the prepared loaf pan and bake for 45 minutes. Cool slightly. Remove from the pan and cut into slices. Cook the peas according to package directions, and whiz in your food processor then add to the White sauce and re heat. Place a slice of salmon loaf on each plate, and pour the sauce on top. Serves 4 to 6.

(Adapted from the American book “The Dysphagia Cookbook— great tasting and nutritious recipes for people with swallowing difficulties”) Elane Achilles ED.D Cumberland House Press, obtainable from Amazon.
Many very good things come in small packages and this new book by the Director of the MND Centre and the MND Specialist Nurse at the John Radcliffe Hospital is most certainly a very good thing indeed. It is timely and very well written. For those seeking advice, guidance or information on MND, there are 150 pages of sound and well researched advice, based on the clinical care given by the MND team at Oxford.

Dr Talbot is a neurologist and an international authority in this rare and disturbing disease, seeing people referred to him from all over the country at the John Radcliffe Clinic. Rachael Marsden is a highly experienced Nurse Practitioner, who co-ordinates the wide activities of the clinic.

Between them they have written the A-Z of MND – “all the information you need, straight from the experts” as the publishers, Oxford University Press, state. The book is in the “The Facts” series, which covers some 24 medical conditions, all written by specialists in the field.

Whilst the Internet can be helpful in seeking information, we all know that the quality of such information is very variable. So it is by far the wisest to take advice from a professional team such as Talbot and Marsden. The subject is dealt with very sympathetically, and many individual patient ‘journeys’ are described, illustrating the very variable nature of MND. Maintaining well-being is paramount and practical matters are well addressed such as how to obtain the correct type of wheelchair, if this becomes necessary. Delicate subjects are covered very sympathetically as they apply both to the person with MND and those caring for him or her.

There is an excellent index, covering every aspect, based on a series of commonly asked questions in the clinic. A section on alternative therapies gives very wise advice. Clinics vary according to the resources available and the authors describe their multidisciplinary team, physio, dietician, respiratory care, speech and language therapy, occupational therapist – all see people with MND at the clinic – a veritable ‘one stop shop’ which is greatly appreciated by patients and families. Reassuringly we are told (p 21) that “when there is no family history of MND the likelihood that subsequent generations are at risk is very small”. There is much practical help re driving, travel, holidays, accessing benefits, grants and full internet links for further help.

To sum up, a most valuable little book for all those involved with MND well worth the cost – about £13.

Reviewed by Anne Silk.
We would like to say ‘Thank you’ to…..

Family members,
Friends
Neighbours
Professionals or providers who have given extra care………
Runners, walkers , fundraisers, collectors
Employers
Businesses, shops
Members of Parliament
Celebrities…………

INVITATION

Can you think of a special person or people you would like to acknowledge for their particular support and kindness in the fight against Motor Neurone Disease - or possibly any of the above who could help?

We would like to invite you and your guest to a special ‘Thank you’ event on Saturday 5 July at the Holiday Inn, Oxford to which all our members are invited. The Oxfordshire Branch would like to thank every one of the membership, as well as other individuals and organisations, for their valuable support for the Association. Even if you cannot come, please make a nomination for our ‘Thank you’ display.

If you would like to invite someone, please let us know the name and address and also your own, so that we can send a special invitation or send it to you to give to them. Alternatively fill in the following form and return it by 23 June if you do not need us to send the invitation.

Come and celebrate many supporters’ contributions with a strawberry tea party on a summer afternoon - rain or shine!

CUT OUT AND SEND OFF!!

Oxfordshire Branch – MOTOR NEURONE DISEASE ASSOCIATION

___________________________________________ would like to attend

A special Thank you event on
Saturday 5th July at 2pm at the Holiday Inn, Peartree Roundabout, Oxford

We will be bringing ____________________________

(name/s of guest/s)

or

I would like to nominate ________________________________________________________ for special thanks although they/we cannot come.

Please RSVP by 23 June to Lesley Ogden Gilmore Cottage, South Street, Blewbury, OX11 9PR Telephone:01235 850372
Hello from the Association Visitors in the Oxfordshire Branch.

There are six of us and most of us have direct experience of caring for a friend or relative with MND; so we are aware of the practical, financial and emotional issues, the implications of living with the disease and the problems this can bring. We cover the whole of Oxfordshire from Banbury in the north to Henley in the south and from Thame in the east to Burford in the west. We sometimes travel into nearby counties where no visitor is available. We can do home visits or maintain a link by phone or e-mail or all three. We can be flexible to your needs.

As a group we meet regularly to keep ourselves up to date and usually the Regional Care Development Adviser, Fiona Turner, attends the meetings. We also have direct contact with the Care Centre through Rachael Marsden. We set up a Carer’s Group in 2005. These meetings, which we continue to support, are currently held every three months. Our referrals come from the MND Care Clinic or our Regional Care Development Adviser Fiona Turner. We are here and usually available and if we cannot help we probably know someone who can. Stella Waterer 01608 677209

PAUL WILKINSON WHO HAS MND WROTE A VALENTINE’S DAY POEM TO THE PEOPLE OF SWINDON

We are all products of our own endeavours,
Create and build an attitude of strength,
courage and infinite possibility.
We cannot be who who we need to be
By remaining who we are.
Change the way you look at things
And things you look at will change.

My illness is but an itch that I scratch now and again,
I barely notice it,
I am too busy seeing to the wants and needs of my heart.

When death comes it will find me
very busy
Enjoying life

My death will not be tragic,
For how can it be, for I have allowed nothing to die
within me.

The way I pray is not what I say to God,
It is what I do with my life in his honour.

The legacy I leave this world is not what thee can see,
But what the heart can feel

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ASSOCIATION VISITOR TRAINING

It is very rewarding being an association visitor and we always need new people who are willing to undertake a short training under the auspices of the Motor Neurone Disease National Office. If you think you are able to do this, please get in touch with Stella Waterer, Rachael Marsden or Fiona Turner.

If you have received this newsletter in error
OR
Your mailing details have changed please contact:
Jackie Reeves
01993 868768
Jackie.reeves@which.net