

# MOTOR NEURONE DISEASE ASSOCIATION



## South & East Somerset Newsletter

### Message from chairman

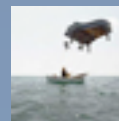
Happy New Year. I hope you are not at all confined to barracks by the snow but it was lovely wasn't it? It makes my spirits soar – until it goes slushy that is, but it stayed a bit longer than usual.

It's been a busy year for the committee so far. We have been fortunate to be named by the Mayor of Yeovil as one of his charities but this of course means some input from us. Before Christmas it was the Mayor's Ball where we ran the tombola. We also helped out at a swimathon. In the New Year we have run a tombola and raffle at the Mayor's Concert at the Octagon. It was a marvellous occasion where we were able to see so much of Yeovil's talent. The bulk of the work always falls on Wendy, our fundraiser, so many thanks to her. Next we will be entering a couple of teams in the Mayor's Quiz and running yet another raffle – so if anyone has unwanted gifts around we would be grateful; our cupboards are bare! Or how about joining us at the Quiz?

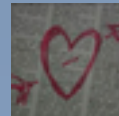
We had a great Christmas dinner at the Camelot and I recommend that you join us next time if you are well enough. Meanwhile our AGM is coming up. This is often sparsely attended but it is a great chance for you to tell us what is good and bad about our organisation – or provide us with suggestions – either for fundraising or how we may serve people with MND better. We will be having a speaker from National Office and this usually a good chance to find out about future developments. We would love to see you there.

**Meg Longman**

## Spring 2009



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And more...

## Murphy's Other 15 Laws



1. Light travels faster than sound. This is why some people appear bright until you hear them speak.
2. A fine is a tax for doing wrong. A tax is a fine for doing well.
3. He, who laughs last, thinks slowest.
4. A day without sunshine is like, well, night.
5. Change is inevitable, except from a vending machine
6. Those that live by the sword get shot by those who don't.
7. Nothing is foolproof to a sufficiently talented fool.
8. The 50-50-90 rule: anytime you have a 50-50 change of getting something right, there's a 90% probability you'll get it wrong.
9. It is said that if you line up all the cars in the world end to end, someone would be stupid enough to try and pass them.
10. If the shoe fits, get another one just like it.
11. The thing that comes to those that wait, may be the things left by those who got there first.
12. Give a man a fish and he will eat for a day. Teach a man to fish and he will sit in a boat all day drinking beer.
13. A case for holding dead batteries.
14. The shin bone is a device for finding furniture in the dark.
15. When you go into court, you are putting yourself in the hands of twelve people who weren't smart enough to get out of jury duty.

**Thank you to my friend Alan Fisher.**

## Daisy is Waiting

This advert was in the Atlanta Journal in America.

**SINGLE BLACK FEMALE** seeks male companionship, ethnicity unimportant. I'm a very good girl who LOVES to play. I love long walks in the words, riding in your pickup truck, hunting, camping and fishing trips, cozy winter nights lying by the fire. Candlelight dinners will have me eating out of your hand. I'll be at the front door when you get home from work, wearing only what nature gave me. Call me on (404) 875-6420 and ask for Daisy, I'll be waiting.

Over 15,000 men found themselves talking to the Atlanta Humane Society about an 8 week old black Labrador retriever!

**Thank you to Edward Thring.**



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## Another Miracle



A priest was speeding down a motorway when he was stopped by the police. The officer smelled alcohol on his breath and saw empty wine bottles on the floor. "Sir, have you been drinking?" "Just water" said the priest. "Then why do I smell wine" said the officer. The priest thought rapidly. "Good Lord! He's done it again"

**Thank you Meg Rogers.**



## Italian Footballers and MND

Italy is investigating a mysterious epidemic among former professional footballers, dozens of whom have been killed by a disease that paralyses victims.

A climate of fear and suspicion hangs over the stadiums. According to one theory, the disease might be linked to pesticides used on football pitches. Others suggest it could be a result of doping or physical injuries from tackles or repeatedly heading the ball.

Adriano Chio, a neurologist, says that footballers in Italy are seven times more likely to develop motor neurone disease than others. Midfielders seem particularly vulnerable, perhaps because they are tackled more than other players.

Christopher Shaw, professor of neurology at King's College London says "there's been a suspicion for a long time that sportsmen are susceptible".

Matthew Campbell, a reporter with the Times newspaper writes that a senior doctor has urged the FA to investigate whether sport contributes to MND. The FA are involved with a ten year study on how "heading the ball affects the brain" and later this year they will be meeting to assess the preliminary results. Adrian Cooper, a spokesman for the FA said it had no plans to conduct a "specific MND study at present".

Watch this space.



## At a Cinema Near You

The first ever UK broadcast ad created to raise awareness of MND is currently being shown on 70 cinema screens across England and Wales.

The 90 second advert is call '*Sarah's Story*'. It is intended to convey the emotional and physical impact of a diagnosis of MND and thus raise awareness amongst the general public of this devastating condition. To many it will be shocking to watch.

The ad has been created at virtually no cost, with free support from within the advertising and film industries.

For a list of participating cinemas go on line at [www.mndassociation.org](http://www.mndassociation.org)

The MNDA is hoping to create more opportunities for the public to see this film over the coming months. If you'd like to help with this by hosting a showing of the film at a local venue, please contact the communication Team on 01604 611 839 or email; [communications@mndassociation.org](mailto:communications@mndassociation.org)

## Take Part in MND Research

Dr Martin Turner is looking to enrol 70 people with MND and 25 healthy volunteers to take part in a biomarker research project.

Dr Turner is based at the University of Oxford. Identifying a predictable disease specific “fingerprint” or “biomarker” is essential to MND research. This is a unique set of substances that help identify whether someone has MND.

His project aims to discover a test to speed up the diagnosis of MND, to understand how the disease spreads and to monitor its activity. The MNDAs are very excited about the prospect of this study, as there is currently no diagnostic test available.

Those involved in the study will be invited to attend the John Radcliffe

Hospital in Oxford for one full day every 6 months. Therefore realistically, anyone taking part should live no further than 150 miles from Oxford.

Dr Belinda Cupid, our research Manager, said “we regard this study as extremely important. It is a great opportunity for people with MND to be actively involved with research. With your support, this study has the potential to play a pivotal role in the discovery of a biomarker for MND”.

If you want to learn more about this project and how you can get involved, please go to the research project’s official website at [www.biomox.net](http://www.biomox.net).



*Dr Martin Turner is looking to enroll 70 people with MND and 25 healthy volunteers to take part in a biomarker research project.*

## NICE to Focus on Ventilation

The National Institute for Health and Clinical Excellence has been asked to prepare guidance on the use of non-invasive ventilation (NIV) for MND.

This is good news and comes at the end of a long process to persuade NICE that NIV is an important treatment for people with MND but that not everyone can currently access it. However, we have recently learnt that work on the guidance might not start until next year and the MNDAs are looking at how to bring this forward.

To recap, clinical research published in 2000 showed that NIV can both significantly improve quality of life and extend survival for people with MND. However, access to NIV is patchy, with many people denied access to this potentially effective treatment.

We want NIV to be available to everyone with MND who could benefit so in 2006 we suggested it as a topic for NICE to produce guidance for the NHS.

We have been extremely frustrated at the length of time it has taken for this process within NICE but were delighted when late last year it was announced that NICE would produce guidance on NIV.

Work to improve respiratory support for people with MND forms part of the Association’s Respiratory Management Campaign. As well as persuading NICE to produce guidance on NIV, the campaign also aims to educate healthcare professionals to the benefit of respiratory support for people with MND.



We will be campaigning hard to ensure that guidance on NIV is produced by NICE as soon as possible and hope you will support us in this campaign.

## Items for Sale



The MNDA offers a free advertising service but cannot accept Responsibility for the condition of items advertised. Arrangements are strictly between buyer and seller. To advertise send details to Sue Gayton on 01604 611 826.

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## Conference Diary Dates

The following dates and venues have been set for the Spring Conferences 2009. If you will be wanting to come please phone Lynda Clark on 01935 424 364 nearer the dates to confirm the venues.

5 April	North East
19 April	South West
10 May	South East
17 May	North West

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## Promoting MND Connect

Please remember to use MND Connect for support and information. They are a very helpful resource for people living with MND and Professionals.

Ring the team on 01604 611 681 or email [volunteering@mndassociation.org](mailto:volunteering@mndassociation.org)

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## Right to Fly



Under new European law, if you are disabled or have difficulty moving around, you now have improved rights to assistance when you fly to, from and within Europe. For more information go to [www.equalityhumanrights.com](http://www.equalityhumanrights.com)

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## Dedicated Consultant for MND

Jean Worker has informed me of a bi-monthly clinic held at Frenchay Hospital for people with MND. If you would like to attend ask your GP to refer you.



## The Over 60's

We were born before television, before penicillin, polio shots, frozen food, Xeros, plastic, contact lenses, videos and the Pill! Before radar, credit cards, split atoms, laser beams and ball point pens. Before dishwashers, tumble driers, electric blankets, air conditioners, drip-dry clothes and before man walked on the moon!

We got married and THEN lived together. We thought fast food was what you ate at Lent, a Big Mac was an oversized raincoat and “crumpet” we had for tea! We existed before house-husbands, computer dating – when a meaningful relationship meant getting along with cousins and “sheltered” accommodation

was where you waited for the bus!

In our day, cigarette smoking was fashionable, grass was mown, coke was kept in the coal house and a joint was a piece of meat you ate on Sunday sometimes cooking it in a pot.

Rock music was a fond mother’s lullaby, Eldorado was an ice cream, a gay person was the life and soul of the part while AIDs just meant beauty treatment of help for someone in trouble!

No wonder we are so confused and there is a generation gap.



## Did You Know?

Former Prime Minister John Major failed the test to qualify as a bus conductor.

Bobby Leach, the first man to survive a trip over Niagara Falls, went on a lecture tour and eventually died after slipping on an orange peel.

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## Future Events

### **Committee Meetings**

These will be held at 7.15pm at  
19, Elmleigh, Yeovil, BA21 3UJ

**Monday 9 March 2009**

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## Annual General Meeting, Saturday 14 March 2009

### **Vicarage Street Methodist Church Hall**

Yeovil, Somerset, BA20 1JT  
2pm – 4pm

We hope to see you at this meeting. We have 3 speakers: Sarah Hampton from National Office who is the Regional Fund Raising coordinator. Mr J Burgess who will talk about his experiences as a Freelance Journalist, and myself who will report back on the International Symposium. We will finish with our traditional cream tea.

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## Quiz 6 March

There will be a Fish and Chip Supper and Quiz night to be held at the Yeovil Town Football Club. A team of up to 6 people. Organised by the Yeovil Mayor. Please phone Wendy Knudson on 01935 849 048 to book a table and for more information.

## The Committee

Patron	David Laws MP
The Chairperson	Meg Longman
Treasurer	Edward Thring
Vice Chair	Margaret Small
Secretary	John Hayward
Contact Person	Lynda Clark 01935 424 364
Newsletter Contact	Lynda Clark 11 Compton Road Yeovil, BA21 5BZ
Fundraising Co-ordinator	Wendy Knudson 01935 849 048
Association Visitors	LyndaClark Lynda Riley

This is not an official MNDA document. Any comments or suggestions put forward are those of the editor and should be treated as such. Please refer to your medical practitioner for all Medical queries.