



## South & East Somerset Newsletter



### Chairman's Report

Christmas is fast approaching and I have lost a whole year somewhere but it has been fun.

The committee has had a quiet six months with fund raising thanks to families raising money for us. The best response to fund raising events are always when a family of a person suffering with Motor Neurone Disease is involved. As a result we have been able to help provide equipment, holidays and financial help for those who need it.

Unfortunately we lose several friends each year and there are always more people with the disease. Our thoughts and prayers are with all the families this time of year and I am sure you would like me to thank the 2 Lyndas for all the support and advice they give.

A peaceful and Happy Christmas to you all.

**Meg Longman**

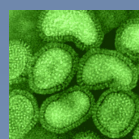
*Season's Greetings*



### Winter 2009



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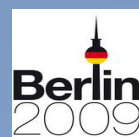
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## 30<sup>th</sup> Anniversary

Thirty years after they first started the MND Association our founder members have filmed a very special birthday message. In the film they each tell their own personal stories and describe how they hope that everyone watching will help continue our story.

The Association was started by volunteers and it is through working together that we will beat this deadly disease.

Visit our website and view their very special birthday message. [www.mndassociation.org](http://www.mndassociation.org)

## Spring Conferences

These will be held during April and May 2010.

These popular one-day events are primarily aimed at people with MND, their families and carers although all interested parties are welcome to attend. The conferences provide the opportunity to learn more about MND care and research, while sharing experiences of living with MND and socialising with friends.

This is a great way to be introduced to the Association and an opportunity to network with local branch and group members and staff.

Details of events are currently being finalized. Registration forms and further information will be available on the website [www.mndassociation.org/conferences](http://www.mndassociation.org/conferences) in the new year. We look forward to welcoming you to one of these events during 2010.

For further information please contact Chris Maden on 01604 611822 or [conference@mndassociation.org](mailto:conference@mndassociation.org)



## Sex and Relationship

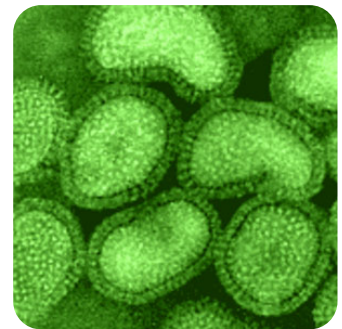
A new information sheet, Sex and Relationships (information sheet 20) is now available.

It deals with the complex issues surrounding relationships when one partner is diagnosed with MND.

For more information or to order a copy please contact **MND Connect on 08457 626 262**.

## Flu Immunisations

The NHS has now got the swine flu and seasonal flu vaccines. People who are at risk should contact their surgery if they have not yet been contacted. It is strongly recommended that all people living with MND should have the vaccine.



## Blue Badge Map

DIRECTGOV has announced major improvements to its Blue Badge map to help disabled people travel across the UK more easily.

Disabled football fans can now use the map to find out about a stadium's accessibility before going to games. And it's good news for train travelers too, as the new map gives information about more than 2000 train stations. This means disabled people can find out about station facilities and can book direct assistance in advance

[www.direct.gov.uk/bluebadgemap](http://www.direct.gov.uk/bluebadgemap)



## Lithium Trial

**In September, researchers leading the North American Lithium clinical trial announced that they are stopping their trials. It has been discontinued because preliminary results do not show the level of benefit that the trial specifically set out to demonstrate. It has not been stopped because of any concerns about patient safety and the UK Lithium trial will continue.**



The UK trial is being run differently to the USA trial. In the UK the researchers will observe the effects of the drug over 18 months, therefore detecting any smaller but nonetheless important effects. This trial is funded by the MND Association and will provide neurologists with vital evidence about this potential treatment.

Recruitment for the trial closes soon and more participants are still needed. The trial is open to people with ALS (the most common form of MND) who;

- Experienced their first symptoms between 6 months and 3 years ago.
- Are taking Riluzole but are not already taking lithium.
- Are not using non-invasive ventilation.
- Do not have a peg.

The nearest trial centres to us are Oxford and Plymouth. Participants would be on trial for 18 months and would need to travel to the centre 14 times during this period, including weekly visits for the first 4 weeks. Travel expenses can be covered.

## Build-UK Chat Forums

[www.magimedia.co.uk/buildforum](http://www.magimedia.co.uk/buildforum)

Build-UK is a fabulous forum for people with MND and their carers.

There are many members, some who have had MND for years, therefore they have a wealth of experience and many tips for coping with the disease.

There is a very useful facility where you can look back through earlier posts about particular things and view the comments made and advice given.

It's a friendly and lively forum with many very caring people who want to share and help where they can. It's definitely worth a look.

Thanks to Rachel and Mark for sharing this information.





## Christmas is Just A Click Away

**Remember to encourage your friends and family to order Christmas cards and MND Association awareness-raising items online.**

This research study aims to uncover more about the lifestyle and environmental factors that people are exposed to that may contribute to why they develop the disease.

Just visit our Christmas collection at [www.mndassociation.org/shop](http://www.mndassociation.org/shop)

There is a wide range of Christmas cards to suit all tastes, wrapping paper and numerous awareness-raising items featuring our new logo. There's a selection of gift ideas for men, women and children – many at discounted prices.

## Stem Cell Breakthrough

New that researchers have successfully transplanted motor neurons from embryonic stem cells in to mice has been welcomed with caution by the MND Association.

Working primarily to indentify treatments for spinal muscular atrophy with respiratory distress type 1 (SMARD1), a team of Italian researchers believe their work also has relevance for potential treatment for patients with other motor neuron diseases.



The researchers transplanted motor neurons derived from healthy mouse embryonic

neuronal progenitor stem cells, into the spinal cord of mice with the SMARD1 gene before the mice were displaying any symptoms of the condition. These stem cells are one which have already been predetermined to become nerves yet still need some coaxing to become motor neurons.

Half of the mice with the transplanted motor neurons were also injected daily with a number of drugs designed to promote nerve growth and to attract the growing nerve extensions towards the muscles the researchers were targeting. After the motor neurons had been transplanted, the mice were tested for their weight, muscle function and survival against the SMARD1 gene that did not have the transplant known as the control group.

The team found out that after transplantation, both groups of mice survived 30-40% longer and weighed significantly more than the mice from the control group. They also found that some of the new motor neurons formed functional connections with the muscle cells the researchers were trying to target.

In comparison with mice from the control group, the motor neurons in the mice which received the transplant were also larger and more plentiful. The researchers suggest that the protective effect of the transplant were two fold; firstly, the newly formed connection of the motor neurons to the muscles; and secondly an enhancement of protective factors caused by the drugs injected into the mice.

Although the results from this study suggest the transplantation, or transplantation in combination with drugs increases survival in mice with SMARD1, the researchers explained they do not as yet understand how the two protective mechanisms work together.

Dr Brian Dickie, our director of research development, commented “this is very promising work. Not only have the researchers managed to direct transplanted motor neurons to connect with their target muscles in appreciable numbers, but they have also been able to demonstrate an improvement in muscle function and survival in a model of motor neuron degeneration”.

Brian, however, is cautious about the potential for transferring these advances to MND in the near future: “Guiding motor neurons and establishing new neuromuscular connections over a distance of a couple of centimeters in a young mouse is very different from attempting the same in human motor neuron disease – especially in adults when the transplanted neurons have to grow up to a metre to reach their target. That is a substantial hurdle we still need to overcome.

For any further information please contact our research development team at [research@mndassociation.org](mailto:research@mndassociation.org) or ring 01604 611880.

## International Symposium

**Berlin, Germany 8-10 December 2009**

National Office organise the symposium every year and it is regarded by the global MND research and health and social care communities as THE conference to hear about and discuss advances in their respective fields. The spirit of the symposium is innovation and collaboration and the format of our event provides researchers with the opportunity to forge new national and international collaborative projects with the ultimate aim of understanding and defeating MND.



Kelly Johnston the Research information Co-ordinator will be writing a daily blog with the latest news from the conference. You can read it by going to the “[My Symposium](#)” section on the website. From the symposium web pages she will also be bringing you personal opinions from the movers and shakers in MND research.

## What do you think of your GP?

Patients can comment on how easy it is to get an appointment, staff behaviour and patient involvement at any of England’s 8269 GP practices.

People can recommend their local medical centre or criticize it, using a new tool available on NHS Choices.

Visit [www.nhs.uk/pages/homepage.aspx](http://www.nhs.uk/pages/homepage.aspx)





## Joke Time

A duck walk into a pub and orders a pint of beer and ham sandwich. The barman looks at him and says; “hang on, you’re a duck!”

I see your eyes are working” replies the duck.“

And you can talk! exclaims the barman.

“I see your ears are working too, but if you don’t mind I would like my beer and my sandwich please”.

“Certainly, sorry about that, it’s just we don’t get many ducks in this pub. What are you doing round this way?”.

“I’m working on a building site across the road” the duck explained. The flabbergasted barman wants to learn more, but takes the hint when the duck pulls out a newspaper from his bag and starts to read it. So, the duck reads his paper, drinks his beer, eats his sandwich bids the barman good day and leaves.

The same thing happens for 2 weeks, until the circus comes to town. The ringmaster comes into the pub for a pint and the barman says: “I know this duck that could be brilliant for your circus. He talks, drinks beer, eats sandwiches, reads the paper and everything”. “Sounds marvelous” says the ringmaster. He handed over a business card. “Get him to give me a call”.

The next day when the duck arrived her was given the card. “The circus! Is that the place where animals live in cages, the humans in caravans and the tent has sides and a canvas roof with a hole in the middle?”

“That’s right!” says the barman.

The duck shaking his head in amazement says: “what on earth would they want with a plasterer?”

## Future Meetings

### **Committee Meetings**

Future dates to be confirmed

### **Support Meetings**

Lynda Riley, also an Association Visitor and myself hold a support meeting for people living with MND, their family, friends and carers. This is held alternate months at the Rocky Mountaineer Garden Centre in Wells. We meet very informally from 2.30 – 4.00pm.

People who attend say they find the meeting very inspirational and swap ideas for different methods of coping with various disabilities.

We would love more people to attend. If you are interested please let me know. (01935 424 634). Transport can also be arranged if enough notice is given. We look forward to seeing some new faces.

**Lynda Clark**

### **Quick Joke**

A Sunday School teacher was telling how Lot's wife looked back and was turned into a pillar of salt.

"That's nothing", said one boy, "my mother was driving the car the other day and she looked back and turned into Telegraph pole".

**Thanks to Meg Rogers**

## The Committee

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