

July 2008

ISSUE No 4

## Southampton and District Branch

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### Diary dates

The Branch holds open meetings at Bedford House from 7.30 pm to 9.30 pm on the second Tuesday of every month. Dates for 2008 are: 12 August, 9 September, 14 October, 11 November and 9 December.

# Come to the Annual Conference

At the MND Association, people tell them how much they value their support as it means they don't have to feel alone on their journey with MND. That's why the theme of the Annual Conference is *With you all the way!*

This year's one-day Annual Conference, to be held on Saturday, 20 September at the Barcelo Daventry Hotel in Northamptonshire, focuses on all the help and assistance available to people on the journey with MND.

An exciting programme of speakers and workshops is being lined up for the popular annual get-together, all aimed at giving practical advice and support.

The Annual Conference is the one time in the year when all those involved in the MND Association come together – people with MND and their carers, volunteers, staff and Trustees. There's always a supportive, "family" atmosphere, and those who come find it informative, friendly and fun.

The Conference is excellent value for money, with a delegate fee of just £32 - £27 if you register before 31 July – which includes all sessions and workshops, refreshments and lunch, and a three course dinner and cabaret in the evening.

If you'd like to stay over, you can book accommodation at the Barcelo Daventry Hotel for a reduced rate of just £70 single / £80 double/twin, including breakfast.

For more information or to register, log on to [www.mndassociation.org/annualconference](http://www.mndassociation.org/annualconference), or call the Conferences team on 01604 611845 or 622822, or you can email [conference@mndassociation.org](mailto:conference@mndassociation.org)

If you're a member of the Association, you will receive a full programme and registration form with the summer edition of *Thumb Print* – due out by the end of July.

### From Rosemary Rockett

June has proved to be a very busy month, the Coffee Morning on June 19th was very well attended and every one enjoyed it, the next ones are July 31st, September 4th, and October 2nd and held as usual at St Marks Church Hall in Archers Road from 11am - 12:30pm.

On Friday 20th June the Branch did their *Walk to d'feet* around Southampton Common. 23 of us met at the Cowherds Pub in The Avenue; we each paid £5 to join in and collected £125, which was not a bad effort.

On Thursday 26th we were invited by Captain Phillip Holliday, the Southampton Harbour Master, to welcome in the Pedal the Ports Tandem Riders into Southampton Docks. A team of riders were doing a 1,600-mile ride around all 21 of the APB ports as a tribute to Nick Palmer who was the director at the Grimsby Port who unfortunately was stricken with this terrible disease.

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We arrived at the docks about 3pm and were given tea coffee and biscuits in one of the rooms in the control tower, the views were fantastic - the Queen Elizabeth 2 was so close you felt you could reach out and touch her. At this point there was a fire alarm and it was everyone out, it turned out to be a false alarm in the boiler room, but it all added to the fun. We were then taken to the real hub of the building, right to the top of the tower where all the real work is done, it really was amazing. The officers there told us how it all worked.

We then had to decamp to another building as the riders were due to arrive, they came across the Solent from Hythe on a launch, two tandems and about six bicycles, they were welcomed by Mr Doug Morrison the Port Director. It was inside again and we were treated to a lovely buffet and lots of chat with some very interesting people.

I was told that the expected amount of the overall collection would be within the region of £100,000 and it was to be split between MND and a new Research Centre in Sheffield.

My husband and I, together with Maria and her two daughters, are off on holiday for two weeks so we will not see you at the July meeting, however I hope you will enjoy the talk by a hunkie fireman on Fire Safety.

See you all in August.

Rosemary

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## **From Valerie, a new Branch member**

*Rosemary Rockett asked if I would like to attend a Focus Group being held by Hampshire Primary Care Trust at Sparsholt. I thought I would combine this report with the request the Branch made for a piece from a new member.*

As a relatively new member of the MNDA, I was diagnosed in August last year with the variant PLS, I would just like to praise the work of the Southampton Group.

The first fortuitous contact was with Rosie Perrett when she came to deliver the lifeline I hired from Winchester CC. She explained about her involvement with the MNDA in Southampton and suggested my daughter Jane and I might like to come along to the next monthly meeting. Our reception couldn't have been warmer and we felt like part of the group by the time we left. What was striking was how passionate everyone was about ridding the world of MND but they are intent on having fun while they do so.

Rosemary Rockett and Tricia Churchill visited me at home a few weeks later and were able to put my mind at rest that Jane and I weren't going to have to deal with MND alone. Phew!

I have enjoyed reflexology care of Maria Stott, delicious cakes at the coffee mornings and joined a happy band of strollers around Southampton Common on a fund raising evening. Sadly it was raining and possible donors had stayed at home.

Rosemary Rockett suggested I might like to attend a Stakeholder Group meeting looking at Neuro-Physiotherapy being held by Hampshire PCT at Sparsholt on 26th June. The participants were drawn from users of Neuro-Physiotherapy (or should I say those who would like to be users) and professionals. The morning session looked at the current position, gaps and issues and what works well/good practice. The afternoon covered how the suggestions could be adopted by the PCT.

By far the largest neurological group represented was those with MS but many of the issues raised were relevant to other conditions. There was felt to be a lack of physio treatment for neurological patients with many being booked in for say six sessions when on-going treatment would be more beneficial or treatment made easily available when the patient deemed it necessary. It seems the system is geared to episodes instead of ongoing care/prevention.

Comprehensive information should be easily available as to what physio treatment is available and where. Another need was identified as respite for younger users rather than them being bundled in with the 70+ age group.

The leader, Sue Damarell-Kewell, Director of Systems Management for the PCT, undertook to circulate during July a summary of the workshop and provide action plans for the short, medium and long term. I will pass on these when they become available.

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## **From Su Starkey, Volunteering Development Coordinator (South West)**

### **Regional Care Development Adviser – Interim Cover**

Many of you will know that Karen Wetherick, our Regional Care Development Adviser, recently left us for pastures new - she will be a hard act to follow! Interviews for her successor were held in Northampton in mid-June, and a successful appointment was made from a very strong field of applicants. More news to follow when we have it.

Before she left, Karen provided MND Connect with a comprehensive briefing on the Southampton area, and the MND Connect advisers will be providing interim cover until the new appointee takes up her post. MND Connect is available for anyone – people living with MND; their families and carers; health and social care professionals seeking guidance on matters relating to MND; and volunteers involved in the support of people with MND. Please do call them on 08457 626262 if you need any assistance, support or information.

### **Hampshire Branches Strategy Group**

A grand-sounding name for a simple idea! Many of the Branches in Hampshire have mentioned that they would like to do more to support the work of the Association, but that they are restricted by low numbers of volunteers.

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The Hampshire Branches Strategy Group comprises representatives from existing Branches and Groups, along with some new volunteers and Su, our Volunteering Development Coordinator, who have come together to look at (a) how Branches could help each other, for example by sharing scarce resources such as website managers, and (b) where there are gaps in the provision of Association services in the county.

We recognised early on that an area from Winchester to Andover seemed to fall between two stools. People affected by MND in those areas don't tend to look naturally to Southampton or to Salisbury for their support services, and as a consequence, they aren't always linked in with the Association. We have made it a priority to recruit additional Association Visitors for those areas so that we can be more responsive to the needs of people living there.

The Group is also working on an event for the whole of Hampshire. We will be bringing together representatives from the Association's Research team; the Southampton Care Centre and King's in London for a special one-off information afternoon on the 18th August at the Grosvenor Hotel in Stockbridge. If you are a person affected by MND, you should recently have received your own personal invitation to the event, and we hope you will be able to attend. There will also be an opportunity to meet representatives of the Hampshire Branches and Groups, and to learn more about the local support available to you. If you would like to know more about the event, please do contact us here in Southampton.

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## Forthcoming events

**Coffee Mornings:** July 31<sup>st</sup>, September 4<sup>th</sup>, and October 2<sup>nd</sup>.

**Collection** outside Waitrose in Romsey on Saturday 2<sup>nd</sup> August.

**AGM and Annual Conference** Saturday 20<sup>th</sup> September for one day.

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## Branch Meetings

The Branch holds open meetings from 7.30 pm to 9.30 pm on the second Tuesday of every month at Bedford House, Amoy Street, Southampton SO15 2DR.

Bedford House is at the end of Amoy Street, off Bedford Place, and there is plenty of parking which is free in the evenings.

These meetings are open to anyone with an interest in Motor Neurone Disease and provides an opportunity to meet and socialise with those living with MND and those dedicated to helping and supporting them. We usually have a guest speaker and refreshments are provided.

Dates for 2008 open meetings are listed on the front page.

The Branch also organises regular coffee mornings at St Marks Church Hall, Archers Rd, Southampton SO15 2LU

## Association's warning over *Neuratax*

Since the beginning of April, MND Connect and the Research Development team have received several enquiries about a 'treatment' for MND called *Neuratax*. It would seem that this product, available in tablet form, is being heavily promoted on the internet as a highly effective treatment that carries no risk of side effects. It contains several herbs and other 'natural' substances.

There is no evidence whatsoever from either laboratory studies or clinical trials to suggest that *Neuratax*, or any of its ingredients, might have a beneficial effect in MND. In addition, it is important to bear in mind that just because a product is natural, it does not mean it cannot do any harm.

Without clinical trials, the potential side effects associated with a treatment cannot be properly assessed. *Neuratax* is an unproven treatment and we would encourage people with MND to consider with extreme caution the claims made about it.

Should anybody with MND wish to start taking *Neuratax*, they should first discuss it with their GP or neurologist.

Further information on the issues surrounding unproven treatments is available from the new research information sheet U 'Unproven treatments', which can be ordered from MND Connect or downloaded from our website.

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## Trial results

The drug *glatiramer acetate* (also known as *Copaxone*) has recently been tested in a pan-European clinical trial that involved a small number of people with MND in the UK (in London and Sheffield). This drug, which is already licensed for the treatment of Multiple Sclerosis, had shown some promise in the mouse model of MND.

However, in the recent clinical trial, *glatiramer acetate* failed to demonstrate any beneficial effects on disease progression or survival in people with MND. The pharmaceutical company that organised the trial will be writing to all of the participants to inform them of the results

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## Your chance to ask the Experts

On Saturday 1 November, people affected by MND have an opportunity to put their questions to some of the leading researchers and neurologists who are gathering for the International Symposium.

The 'Ask the Experts' session will take place from 2pm to 4pm at the Hilton Birmingham Metropole, National Exhibition Centre, Birmingham. This is a free event open to people with MND and their carers.

Places are limited – online registration is available at [www.mndassociation.org/conferences](http://www.mndassociation.org/conferences); alternatively, call the Conference Team on 01604 611822.

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## Advanced Decisions to Refuse Treatment

Also known as 'Living Wills', Advance Decisions to Refuse Treatment (ADRT), allow individuals to give instructions about any possible medical treatment, should there come a time when they are unable to make decisions for themselves or to communicate them to others.

The Advance Decision to Refuse Treatment (ADRT) Project Team is a small dedicated group of senior healthcare professionals promoting, informing and training professionals about this new statutory right of people to make an ADRT. The team is hosted by Mid-Trent Cancer Network (NHS) and works closely with the East Midlands office of the Care Services Improvement Partnership (Department of Health).

The MND Association is currently working with the ADRT Project Team, to develop a bespoke version of an ADRT form, which will be available in the near future. In the meantime, if you would like to view the ADRT form developed by the Project Team you can view it on line at [www.adrtnhs.co.uk/pages/about.htm](http://www.adrtnhs.co.uk/pages/about.htm)

Do bear in mind that this form only relates to treatment that you **do not** wish to have in the future. If you have any questions about advanced directives, please contact MND Connect, on 08457 626262, e-mail : [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

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## MND Aid Foundation

The MND Association is aware of a website that promotes an organisation called the *MND Aid Foundation* which is in no way connected or affiliated to the MND Association.

The *MND Aid Foundation* describes itself as a "non profitable organisation". It is not a registered charity and we have no knowledge of its credentials. We would ask you to continue to advise people seeking information about MND, either as someone living with the disease, or

a carer, or a professional, to visit our website: [www.mndassociation.org](http://www.mndassociation.org) or contact MND Connect on 08457 626262 or at [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

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## Travel with Confidence

Obtaining affordable travel insurance when you are living with MND isn't always easy. This is largely due to the lack of understanding and knowledge about the affects of MND within the insurance industry.

The MND Association recently made a decision to remove Holiday Insurance Information Sheet from circulation. The Association is in the process of investigating insurance companies specifically offering travel insurance for pre-existing conditions and hope to introduce a new information sheet in the near future.

The MND Association continues to lobby the Association of British Insurers (ABI) and its members to promote equality and fairness, so people living with MND can obtain affordable and appropriate insurance cover in the near future.

The Association would like to take this opportunity to reiterate key points previously highlighted on the information sheet as these are still relevant. When applying for travel insurance you will invariably be referred to a medical screening line. You will be asked a series of medical questions designed to establish how the disease affects you individually. These **may** include the following:

- Do you have a pre-existing condition?
- What type of MND do you have?
- How long have you been diagnosed?
- Have you been given a terminal prognosis?
- Are you awaiting any test results?
- Have you had inpatient treatment within the past three months?
- Questions about your independence.

## Other important things to bear in mind:

In insurance terms, terminal diagnosis usually means you been given less than six months to live. The Association would advise you to say yes, you have been diagnosed with a terminal illness, but make it clear you have **NOT** been given any prognosis. The question about test results will not refer to routine tests which may be carried out during a check up. If you are awaiting other test results, you will **NOT** be offered cover, not even for an ingrown toe nail! Insurers do not like to offer cover to anyone who has received recent inpatient treatment. Insurers may add a high excess to premiums if you have been diagnosed for over 12 months.

### Must do's...

The Association would strongly recommend you obtain at least three quotes and go for the most competitive, bearing in mind the advice given above. When you receive your policy document, check it really does include everything it says on the tin!

- Taking aids and equipment? Think about getting them covered.
- Travelling in the UK? You may still wish to consider taking out cover.
- Want to know more? Please contact MND Connect for more information on travel insurance.
- Had a bad experience?

Sharon Schillerstrom, Care Information Development Manager said: *'I would be really interested to learn about any difficulties you have had when obtaining travel insurance. This will enable us to continue to lobby the ABI and their members on your behalf, so that meaningful changes are brought about in the industry, so people living with MND get the fair deal they so deserve.'*

e-mail: [sharon.schillerstrom@mndassociation.org](mailto:sharon.schillerstrom@mndassociation.org)

or leave a message via MND Connect on 08457 626262.

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## Sharing hints, tips and suggestions

Hints, tips and problem-solving suggestions come from many different sources to help people living with MND manage everyday activities. The best advice often comes from people who have first-hand experience of living with MND. With the help and support of members of the PMA/PLS email support group, we are delighted to introduce you to new pages on our website, to share those useful hints and tips as provided by people living with MND.

Please have a look at our new pages and let us know what you think. If you have anything you'd like to see included, please get in touch, so we can share what worked for you with others. Visit: [www.mndassociation.org/hintsandtips](http://www.mndassociation.org/hintsandtips)

## Council Tax payments

CARERS UK is urging carers to make sure they are paying the correct amount of council tax. It isn't widely publicised, but some carers could qualify for up to 50% off their council tax bills. If you are a carer and want to find out if you should be getting a discount on council tax, contact Carers UK.

## Volunteer driver sought

Peter Farren is looking for a volunteer driver for his new 'Pope-Mobile', (a Citroen Dispatch modified for wheelchair access). He will always be travelling with a nurse. Contact Peter on 023 8086 1313 or e-mail [farandaway06@yahoo.co.uk](mailto:farandaway06@yahoo.co.uk)



## ATTENTION ALL WALKERS!

Want to be part of something special? Then join us in our largest national fundraising event and help us to take a step closer to realising our vision – **A World Free of MND**. We need **your** help to make Walk to D'Feet MND a great success in **your** area.



Looking to support the charity but don't know what to do?



This is an easy and enjoyable way to show your support



A chance to make the most of the great outdoors



A fun, social event open to the whole family and local community

Walks generally take place in or around MND Awareness Week, but can happen anytime between May and September so there is still time to arrange a walk in your area.

For more details contact:  
Trudi Willis, Community & Events Fundraiser  
Tel: 01604 611834 or email: [trudi.willis@mndassociation.org](mailto:trudi.willis@mndassociation.org)

## In a spin...

Fancy getting yourself into a spin with our fantastic **Champagne Cycle Challenge: London-Reims 11-15 September?** 'Get on yer bike' and guarantee your saddle has pride of place in this challenge! £99 registration fee and £995 to fundraise! More information from: Trudi Willis, Community and Events Fundraiser, 01604 611834 or email [trudi.willis@mndassociation.org](mailto:trudi.willis@mndassociation.org)

## Branch Committee

Sue Stone - Chairman  
Maria Stott - Vice Chairman  
Bernice Allison - Secretary  
Nalin Shukla – Treasurer  
*Donations to me at: 5 Maytree Road, Chandlers Ford, SO53 5RT*  
Rosemary Rockett - Branch Contact - 02380 891842  
Tricia Churchill  
Peter Farren  
Gaby Perrett  
Rosie Perrett  
Trudy Evans

## Keep up to date

Visit the branch's website at <http://mndsouthampton.org> for further information and news.

## Material for future Newsletters

The goal is to produce a Branch Newsletter every 6 to 8 weeks, depending on how much material is sent in.

This is your newsletter and you are most welcome to send in news, letters, favourite recipes, write an article, write a quiz or poem, draw a picture, etc. Please also send photographs if available.

Please email any material to: [tricia\\_churchill@btinternet.com](mailto:tricia_churchill@btinternet.com)

or post to:

Tricia Churchill  
The Wellhouse  
102 Christchurch Road  
Winchester SO23 9TG

Peter Farren says: *Here's an invite to come my birthday bash.  
Invite friends, the more the merrier. Hope I see you there.*

