

February 2009

ISSUE No 7

Southampton and District Branch

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Branch Meetings

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 2009 are: 10th March, **7th April**, 12th May, 9th June, 14th July, 11th August, 8th September, 13th October, 10th November, and 8th December

Coffee Mornings

19th March, 23rd April. *More dates to follow*

Local conference for people affected by a long-term neurological condition

A note from the Chair

This newsletter is an extra long quarterly edition which in addition to the information pertinent at Branch level, contains a lot of supplementary material provided by the Association which is relevant at national level.

At a local level, we are pleased to supply information on Vitalise, which is a national charity providing short breaks and other services for disabled people and their carers, and which has a local respite centre at Netley Abbey; and secondly to announce a Conference in mid-March organised by the Hampshire Neurological Alliance, titled *Working Together to Improve Neurology Services in Hampshire and the Isle of Wight*, which I think will be of great interest to many of you and aims to take forward the standards of care in this area which is important to us all.

Among other items, the Association has supplied information about *Sarah's Story*, which some of you may have already seen in cinemas, news of the new logo and rebranding of the Association, details on lithium trials and statins, and recent advances in stem cell research and other research projects, all of which is very interesting reading.

As you will see the AGM is to be held in April. It will be lovely to see as

many of you there as possible. Should you wish to come and join the committee or feel you can help with the branch in any way please do come forward.

Calling all you barn dancers. This event will be back this year by popular demand. A date will be posted shortly.

Your committee is working on an event for the Southampton Branch. This will incorporate Walk D'Feet, possibly a balloon release and other fun things. This will all take place locally on one day. More information will be available shortly. Hopefully the only thing that we will not be able to make a certainty will be decent weather.

Please enjoy the newsletter.

Sue

AGM
to be held on
TUESDAY 7TH APRIL 2009
at 7.00 p.m. at Bedford House

The Branch Meeting for April has been brought forward one week to 7th April due to the Easter holidays.

All nominations for the committee to be forwarded to Bernice Allison at berniceallison85@hotmail.com or 5 Wyre Close, Chandlers Ford, Hants SO53 4QR



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.

Speakers at Branch Meetings are:

March – Vitalise

April - AGM and talk by Sue on the Mexico challenge

May - Pat Swadling of Forresters

June – TBA

July – Telecare, Caroline England

The Branch also organises regular Coffee Mornings at St Marks Church Hall, Archers Rd, Southampton SO15 2LU from 11am to 12-30pm. Coffee Morning dates over the next few months in 2009 are Thursday 19th March and 23rd April. Further dates will be advised in the future.

Forthcoming events

These fundraising events are for Trudi and Maria's Arctic Trek:

7th March : Music Quiz at The Gleneagles Pub, Butts Ash, Hythe

29th March : table top sale at Hythe and Dibden Parish Hall, West Street, Hythe, 1 - 4 pm

13th June : 50's/60's rock 'n' roll evening at The Waterside Sports and Social Club, Long Lane, Holbury

From Rosemary Rockett

The recent collection of Green Tokens at the Hythe branch of Waitrose raised £326 and was well worth the effort put in.

Rosemary

Vitalise

Vitalise is a national charity providing short breaks (respite care) and other services for disabled people, visually impaired people, and carers.

It offers inspirational opportunities for volunteers through one of the largest, most diverse volunteer programmes in the UK.

It has five accessible Centres in the UK, each with its own unique character and offering a range of amenities and activities for you to enjoy during your short break.

There is one in Hampshire at: Vitalise Netley Waterside House Abbey Hill, Netley Abbey Southampton S031 5FA



Facing Southampton Water, just a few miles from the vibrant city of Southampton, Vitalise Netley Waterside House is a modern building set amid landscaped gardens.

There is wheelchair access through the gardens down to tranquil Southampton Water. Historic Netley Abbey and Netley village are close by.

It is suitable for adults of any age with physical disabilities.

Level of care

Experienced nursing and care staff are on call to provide assistance 24 hours a day. Volunteers also provide companionship and support for guests.

Our partners at *Refresh* can provide planned breaks and respite care for guests who are severely disabled and ventilator-dependent.

We have highly qualified nursing staff, a full range of equipment and an automatic start diesel mains generator in case of power failure, so that guests can relax and enjoy all the benefits of the Centre without worrying about whether their special needs will be met.

For further information: 023 8045 3686 or visit: www.vitalise.org.uk

Working Together to Improve Neurology Services in Hampshire and the Isle of Wight

A Conference for people affected by a long-term neurological condition.

Monday 16th March, 9.30-16.30

Venue: Alton Maltings Centre, Hants GU34 1DT

Find out all the latest developments!

"this is a chance to have YOUR say on the way social care and health services are provided across Hampshire - the right people will be there to listen!"

This event organised by Hampshire Neurological Alliance (HNA) aims to raise awareness of challenges and issues, faced by the people of Hampshire and the Isle of Wight with a neurological condition, whilst providing an opportunity for a two way communication between people affected by a Long Term Neurological Condition, and those people responsible for supporting their needs.

It will include presentations from people affected by a Long Term Neurological Condition, sharing their experience, and speakers from the Hampshire County Council and Hampshire Primary Care Trust, responsible for providing services and support to this community. There will also be a presentation from a leading neurologist on the status and prospects for research in the field.

For directions to The Maltings see www.altonmaltingscentre.com

The event is free of charge to people with a Long Term Neurological Condition and their carers, and costs £10 for professionals.

A draft Programme and Registration Form are attached at the end of this newsletter on pages 11 and 12.

Closing Date for registration: **7th March**

For further information:
Lisa Goodridge tel: 0790 230 5873
e-mail: lisa.goodridge@pspeur.org

Sarah's Story

We are developing a brand new awareness campaign called Sarah's Story. It follows on from John's Journey and features a film clip that is about two minutes long. It tells the story of the psychological and emotional impact of getting a diagnosis of MND. It also shows different stages of the body's deterioration as the disease progresses.

An actress plays the part of a young healthy woman who is suddenly struck down by the disease. As her body deteriorates we are shown the wasting of her muscles through the body of a person who really does live with MND, Sarah Ezekiel – hence the title Sarah's Story. The sense of the story is maintained because the face of the actress is superimposed on Sarah's body.

The clip has been made for cinema by a film company that has generously donated all its time for free. It is aimed at the general public in an attempt to raise levels of awareness about the disease. The tone is very hard-hitting in order to grab attention.

However, we understand that some members may find it distressing to watch so we're consulting with a number of Branches about the best way to communicate about it within the Association.

Having made the film using donated time, the next challenge is to persuade a cinema chain to show the film for free. We are currently trying to secure this deal and will keep you updated on progress.

Christmas card competition

Have you ever thought you could design a better Christmas card than the ones you've seen for sale? Well here's your chance...

As 2009 is the 30th anniversary of the foundation of the Association,

we're offering promising artists and budding photographers the chance to demonstrate their talents by designing a charity Christmas card for 2009. Designs should be creative and original, incorporating a Christmas or winter theme. We hope to receive a wide range of entries and there are no restrictions on style. Entries must be presented as artwork or photography (20cm x 20cm) and can be traditional or contemporary. The winning designs will be reproduced into 12.7cm x 12.7cm cards.

The categories are:

- Person with MND
- MND Association members and people affected by MND
- MND Association staff and volunteers
- Aged 10-17
- Aged under 10

Winners will be notified by 20 April 2009. Their designs will be mass produced and sold as part of our Christmas Collection.

To enter our Christmas Card Design Competition please send your design (carefully packaged), to Liz Watkins, MND Association, PO Box 246, Northampton NN1 2PR by the deadline of 27 March.

Judging will take place on 6 April.

Lithium in the news

Why lithium?

There is scientific evidence to support the use of lithium as a treatment for MND. Laboratory studies have shown that lithium can have a protective effect on motor neurones. In February 2008, a group of Italian researchers published the results of a small clinical study of lithium. The results were encouraging as they reported that lithium slowed the progression of MND but they need to be considered with extreme caution because the Italian trial had significant weaknesses.

The need for answers

At present, lithium is occasionally prescribed to people with MND to treat accompanying or pre-existing mood disorders. However, online MND communities are now aware of the possible effects of lithium in slowing the disease – and within some patient-group forums, members with the disease are asking how they can obtain lithium without prescription. In some cases, people with MND are obtaining lithium 'off label' at the discretion of their GP.

The story in the media

As you may be aware we have already started to communicate our news to our membership and so communicating this to the media was the next logical step. We held a media briefing in London on 31 October which was well attended by national newspaper journalists. Prof Colin Blakemore, our President, introduced the briefing. Brian Dickie, our Director of Research Development, then followed talking specifically about MND, lithium, and the fact that this is our first Association-funded clinical trial. He also gave the International Symposium a plug too. Prof Nigel Leigh, Director of the King's MND Care Centre, was our MND clinician on our briefing panel. Nigel is leading this trial and he spoke about his involvement.

The briefing was a huge success with all media keeping to our strict embargo so that the news broke on Monday morning – the first day of the Symposium.

Media coverage

Our story received lots of column inches,

with great coverage in: The Times -featuring Mark Carr from Wakefield who is living with MND, The Guardian, Financial Times and the Metro as well as lots of regional newspapers too. Many news websites featured the story including the BBC News, ITN

News, Channel 4 News and the Daily Mail online site.

Our story even got a mention on the BBC Radio 2 morning news bulletin. Lawrence McGinty, science editor, at ITN News covered our story during the ITN News Lunchtime bulletin on Monday 3 November.

Lithium study – what is happening and when?

Thanks to the great media interest in the story, we felt that we needed to give you an update, to let you know what we know so far. As soon as these details have been finalised an Information Sheet will be written and made available. This is likely to be in the New Year.

Much behind the scenes work still needs to be done between obtaining the funding for the trial and being in a position to start recruiting people with MND into the study.

Exactly how the trial will be run on a day-to-day basis, who will be included in the study and which centres will be involved etc needs to be established.

Which centres will be included?

There will be ten centres included in the trial not all of these centres will be MND Association Care Centres. The current list of centres is Newcastle, Preston, Manchester, Liverpool, Sheffield, Birmingham, Oxford, King's College Hospital, National Hospital,

Queen's Square and Plymouth. This list is still to be confirmed.

Who can take part in the study?

Clinical trials are research studies to determine the safety and the beneficial effects of the drug. All clinical trials have inclusion and exclusion criteria, in order to be able to determine a statistically useful outcome of the trial as quickly as possible. Again, although these criteria are to be finalised, it is likely that people with a PEG/RIG or using NIV or

invasive ventilation will be excluded. A limited number of people can take part in the lithium study.

Trials are designed to be able to get answers on a drug's safety and beneficial effects as quickly and efficiently as possible. In order to do this the numbers of participants are carefully worked out. Thus it is also important to point out that even if people with MND meet the criteria to be included in the study, it may not be possible for them to participate due to this limit on numbers.

Lithium can be toxic if the levels in the blood are not carefully monitored. People taking part in the study will need to attend a trial centre regularly for blood tests. Sometimes these tests will need to be conducted as often as weekly.

The limited numbers of participants and the need for regular tests mean that it is unlikely to be feasible for people with MND living further away from a participating centre to be able to take part. This particularly applies to people living in Scotland, Northern Ireland and some parts of Wales too.

I have MND and I'm interested in taking part, what should I do next?

Talk to your neurologist at your next appointment and let them know that you are interested in taking part in this trial. When recruitment begins your neurologist can either consider you for inclusion (if your neurologist is at one of the participating centres) or pass on your details to a local participating centre.

It is important to realise that half of the people taking part in the lithium study will be received a 'dummy' pill or placebo. More information on placebos and why they are used is given in our Clinical Trials information sheet (Information Sheet D).

It's Good to Listen

Where would you be without your closest friends? Who would share your highs and lows, lend support or just be there to listen?

As many of you are sadly aware, a diagnosis of MND can be a frightening and isolating

experience. Sometimes all that people need is a friendly face and a listening ear to make a real difference to their lives. We need people like you to help make that difference. We are currently seeking sociable, caring people to volunteer as Association Visitors (AVs).

AVs play an incredibly important role, providing friendship, advice and support to people affected by MND, both on the phone, via email and face-to-face.

As an AV you will work as part of a close-knit local team, offering a vital link between people with MND, their local Branch and other sources of support. In return for your time, you'll make some wonderful new friends and receive free training, which has won national recognition

Training dates for 2009

- Intro Day: Thursday 2 April
 - Residential: Friday 24 April and Saturday 25 April
 - Follow-up Day: Tuesday 23 June
- London**
- Intro Day: Wednesday 6 May
 - Residential: Friday 5 June and Saturday 6 June
 - Follow-up Day: Thursday 23 July
- The Midlands**
- Intro Day: Wednesday 9 September
 - Residential: Friday 25 September and Saturday 26 September
 - Follow-up Day: Thursday 19 November
- London**
- Intro Day: Saturday 3 October
 - Residential: Saturday 17 October and Sunday 18 October
 - Follow-up Day: Tuesday 8 December

New year, new look



It's what we have all been waiting for! The unveiling of our exciting new look and new logo to help us better communicate who we are and what we stand for.

On 18 February, we launched our new logo to the world, though be reassured not everything will change overnight.

As previously explained, the aim of changing our visual identity – that is, our logo and the colours and look and feel of our materials – is to build further trust in the Association and to reflect our position as a passionate and innovative organisation offering certainty and hope to people affected by MND.

The new logo has emerged as the result of several months of consultation involving volunteers, people with MND and their carers, staff and external audiences. It is a more modern and distinctive logo than our current one, and should therefore help us increase awareness and our ability to raise funds and successfully influence.

The logo is based on the idea of disconnection and connection. MND disconnects people from their own bodies and their lives. The MND Association reconnects people – with friends and family, with their quality of life, and one day, through research, by eradicating the disease. If you are one of the dozens of volunteers who took part in the consultation process, thank you!

All the views that were expressed were fed into the process of deciding which of the suggestions for a new logo would be taken

forward, and the *disconnections / connections* theme came out joint top.

The logo will be rolled out across the Association's communications materials gradually, commencing this month. Not all materials will change straight away. In particular, we do not want Branches and Groups to replace printed materials for the time being. It will save time and money in the long term to roll out the new look gradually. The 'thumbs up' icon has been retained as it is an important heritage badge and internal branding device, in other words, for communications involving volunteers, staff and our membership.

Branches will be able to use the 'thumbs up' on some of their materials, and continue to sell pin badges. We have redrawn the thumb to give it a friendlier feel, and this will be rolled out gradually along with the new main logo. However, we will no longer be using the 'thumbs up' in national external communications.

What do we do with our stuff?

Not all materials will change straight away, as it will save time and money in the long term if we roll out the new look gradually. Continue using pre-printed stationery with the old logo for the time being. To reduce waste in the long-term start using up your old stock now rather than order new, especially in large amounts. We will let you know if there is a cut off time for using up old stock.

Branch/Group letterhead

An updated version will be available from 18 February for new orders. If you still have a stock of the current version, continue to use this until it's all gone, or recycle this and order the new version.

Welcome leaflet, posters, display boards, banners, bookmarks and business cards

These will be updated through this year, and any new orders will take on the new look once it's available. There's nothing you need to do. Once again, feel free

to continue to use your existing material, or as above, recycle.

Branded items for sale

New branded items will be featured in the next sales catalogue for Branches and Groups to order from. This is due out in the summer.

Branch websites and newsletters

Artwork of the new logo suitable for loading on to websites and newsletters will be sent out.

Updated Branch website and newsletter templates will be available in due course.

Can we help further?

For information about the new logo, or a copy of our special leaflet explaining our new identity, please contact the Communications Team on 01604 611839 or email communications@mndassociation.org

For advice on your materials, please contact the Volunteering Team on 01604 611681 or email volunteering@mndassociation.org



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

Appeal boosts funds for clinical trial

On the eve of our Symposium we announced our intention to fund a clinical trial to investigate the effects of lithium as a possible treatment for MND. This is the first time we have been in the position to fund our own clinical trial. Recruitment is planned for spring 2009.

The cost of the three-year trial will be £400,000, despite senior clinicians donating their time to running them. So the Association launched an appeal in the middle of November 2008 to our existing

supporters to help raise the money needed. Thanks to all of you who responded so generously to our special appeal to fund this clinical trial. At time of going to print in January we have raised a fantastic £113,830. It is not too late to support this important clinical trial.

If you would like to receive a copy of the mailing please email our Fundraising Team at fundraising@mndassociation.org

For more information please visit the treatment trials page of the website www.mndassociation.org/clinicaltrials

Well done Ann

Many congratulations and thanks to Ann Tomalin from the West Kent Branch who received a Kent County Council Welfare and Disability award for her work as an Association Visitor. Ann has been a Visitor since 1988.

There were several hundred nominations in the category and Ann was one of three winners! She also received £400 for the Branch. Ann said: *"For me, it's a team win, thanks to everyone in the West Kent Branch. I've got backing from a good Committee and other Visitors. You can't work in isolation, but it is rewarding to have a mention."*

This success reflects not only on the West Kent Branch but on all the hard work our volunteers put in all over the country.

From strength to strength

The recently formed Coventry and Warwickshire Group had its second successful 'get together' in November with 36 people attending, including families affected by MND and numerous health and social care professionals.

Attracting people to Open Meetings and events is something

all Branches and Groups ask us about, so we asked the staff and volunteers involved for the secrets of their success. *"It's about everyone working together,"* said Angela Lea, Volunteering Development Co-ordinator (VDC) for the area. *"We all took time to plan it."* They looked for a good venue (a local hotel) and arranged the meeting for a Sunday afternoon. Margaret McIntosh, the Regional Care Development Adviser (RCDA) promoted the meeting with Health and Social Care Professionals including the Neurology Team at the Coventry and Warwickshire Hospital Trust.

The neurologists, Dr Khurana and Dr Thomas, were asked to speak. Margaret was involved in drafting the invite sent by the Group to members, and to all the people with MND that we are aware of in the area.

The Visitors also worked hard at the meeting, helping to make people welcome. *"It was lovely to have neurologists, people with MND, families, Association Visitors and health and social care professionals all in the same room,"* said Angela. *"It was absolutely wonderful, everyone rallied round,"* said Nerys Watton, Group Contact and Association Visitor. *"Angela has been with us all the way through, from starting out as a Group and has guided us all the way along. Margaret got hold of the consultants and got them to come along."*

Having the consultants at the meeting was an added bonus, as they took the time to speak to people with MND, who appreciated meeting them in an informal setting. It's obviously unlikely that neurologists would attend every Open Meeting, but it's definitely worth inviting them and other professionals. Why not try it for your AGM, if you haven't already?

So, what's the Group's secret? Planning and working together, by the sounds of it. This Group is

clearly going from strength to strength thanks to the support of their VDC, RCDA and their own dedication. Congratulations on a great start!

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, *pictured*, is based at the University of Oxford. In the summer of 2008 he was awarded a joint funded Medical Research Council/MND Association Lady Edith Wolfson Clinical Research Fellowship.

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. We are extremely excited about the prospect of this study as there is currently no diagnostic test for MND. Those involved in the study will be invited to attend the John Radcliffe Hospital in Oxford for one full day every six months.

Therefore realistically, anyone taking part should live no further than 150 miles away 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 www.mndassociation.org/biomarker_project. Alternatively you can visit the research project’s official website at www.biomox.net.

Statins and MND

Statins, which are cholesterol lowering drugs, are known to have adverse side effects similar to some of the symptoms of MND. This has caused many people to question the use of statins in relation to MND.

Do statins influence the progression of MND?

Studies trying to find out whether statin use influences the progression of MND have so far been contradictory. One study suggested that statin use does influence the progression of MND. Conversely, a larger study suggested that the use of statins does not influence the progression of MND. Therefore, unfortunately, the correct answer to this question will remain unknown until further studies have been conducted.

Are statins a risk factor for developing MND?

A recent study conducted by the Food and Drugs Administration (FDA) revealed that there is not an increased incidence of MND for people taking statins as compared with those not taking statins. This means that taking statins is not a cause of MND. We would encourage anybody who has MND who is currently taking statins to speak with their doctor for appropriate medical advice

Advance in stem cell research

On Friday 9 January, heart researchers discussed a recently published advance in stem cell research on the Today programme on Radio 4. Below, is a brief description on what this development means and what it may mean for the future of MND research.

Normally, your bone marrow (which is where stem cells are produced) has a build up of chemicals that stop stem cells from migrating into the blood stream to be used around the body. When things go wrong in the body, stem cells (which can be thought of as emergency service vehicles) are sent to repair the damage caused. Therefore depending on what the problem is, a different service is sent out.

However, the number of ‘emergency service vehicles’ sent out in a disease situation are simply not sufficient enough to repair the system. This can be related to a roaring fire, where one fire engine is not able to subdue it. By manipulating this system, researchers have found a way to select which ‘service’ they require and send out a much larger number to tackle the situation. In theory, this means that in a disease situation, ‘fire engines’ may be chosen to effectively put out/ subdue the roaring fire. For MND research, this means that a proof of principle has been found that it is possible to dramatically increase the number of (selected) stem cells in your body, which could (if developed further) lead to an effective treatment for MND. However, this research is still at a very early stage and requires evidence that the selected service sent out would be able to repair the system as there is no point sending a fire engine to fight a fire without any water!

At a cinema near you now

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 – called *Sarah’s Story* – is intended to convey the emotional and physical impact of a diagnosis of MND, and thus to raise awareness amongst the general public of this devastating condition. Cinema goers are therefore likely to find it unsettling, even shocking, to watch.

The ad is part of a wider campaign being rolled out by the Association during 2009, which will also include a website, media relations and further advertising. The purpose of the Sarah’s Story campaign is to raise awareness of MND and the work of the Association. The ad has been created at virtually no cost, with free support from within the advertising and film industries. Making the film involved people with MND, in particular, Sarah Ezekiel from London, after whom the campaign has been named. There is more information about the campaign at www.sarahsstory.org.uk.

The cinema showings in January and February, which come to an end on 19 February, are thanks to the kind support of cinema advertising company Pearl & Dean. The list of participating cinemas can be found online at www.mndassociation.org/sarahsstory

The ad is rated to be shown only with films of certificate 15 or 18. Late last year, we held viewing groups around the country for Branch and Group volunteers, Association Visitors and people affected by MND. On the whole, the film was positively received, with people generally in favour of it being shown to raise awareness of MND and the Association. If you came to a viewing group, thank you. During January, we once

again recruited the help of Branch and Group volunteers and Association Visitors, this time in disseminating news of the Pearl & Dean cinema showings. This was because we wanted to avoid as far as possible someone affected by MND seeing the ad with no prior warning, and being distressed by it.

If you were involved in disseminating this information more widely, once again, thank you. We are hoping to create more opportunities for the public to see the 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 Communications Team on 01604 611839, or email: communications@mndassociation.org

Individual budgets

The Department of Health has published a report on the Individual Budgets pilot. The pilot was conducted over two years 2006-2007 involving 13 local authorities.

The report doesn't mention MND but does suggest that older people don't find Individual Budgets easy to use and don't like the idea of managing their own support. These are concerns that we have previously expressed on behalf of people living with MND.

Clinical trials

Clinical trials, what are they and how are they organised? This Information Sheet has now been updated to include news on new, ongoing and completed MND clinical trials in Europe and the USA. It is readily available to download from www.mndassociation.org/clinicaltrials Alternatively, if you would like to receive a hard copy please contact MND Connect.

Talking about the end of life

Many people diagnosed with MND may have fears and concerns about dying.

This is understandable, dying is not a subject easily discussed as it raises many issues and feelings. Preparing an Advance Decision to Refuse Treatment (ADRT) may help to open up a discussion with family and health professionals on end of life issues, and its provision can help to bring reassurance to a person who may be concerned about their future healthcare. It will also enable health professionals to ensure that the person's wishes are taken into account. Until the introduction of the new ADRT, the Living Will document was used to convey people's wishes for a time when they may lack the capacity to express this for themselves.

We felt it was vitally important for a new document to be drawn up, because for people living with MND, it is especially important to plan ahead. Many people in this situation fear losing control and not being able to express their concerns or preferences to a health professional. The new document Advance Decision to Refuse Treatment will be legally binding. The majority of the research for this document was undertaken by the ADRT Project Team (Mid Trent Cancer Network www.adrtnhs.co.uk). This was as a result of national guidance in the form of The National End of Life Care Programme

www.endoflifecareforadults.nhs.uk

Our new document has been specifically designed for a person living with MND. ADRTs that meet all the requirements of the Mental Capacity Act will be legally binding on health and social care professionals. This makes the ADRT distinct from other aspects of care planning. Care planning may include statements of values, wishes, priorities and preferences about what is to be done should a person lose capacity at some point

in the future. These are taken into account as part of an overall judgment of best interests but are not legally binding. An ADRT will only become active when the person with MND has lost capacity and is unable to convey their wishes.

People do not need a solicitor to make an ADRT but do need to be over 18 and have full capacity when making it. It is essential this document is witnessed and signed to that effect. The new document will be accompanied by a set of instructions and guidelines to enable a good understanding of how this works. It is a framework of information that could be a starting point or a person living with MND to address end of life issues. The next step would be to talk to the consultant or health care professional involved in their care. To find out more please contact MND Connect.

Visitor development

If you are an Association Visitor, sign up now for your 2009 development day.

This is your chance to meet other Visitors from a wider area, share experiences and have a nice lunch. Of course, it's also an opportunity to keep up-to-date with developments in the Association and wider health community about issues concerning your role.

The dates for 2009 are:

- Thursday 26 March, Taunton / Exeter
- Thursday 23 April, Newark
- Saturday 25 April, London
- Wednesday 20 May, Preston
- Wednesday 10 June, Southampton
- Tuesday 7 July, London
- July (date tbc) Bury St Edmunds
- Thursday 24 Sept, South Wales
- Saturday (tbc) in Oct, Bucks
- Thursday 15 October, Nottingham (Strelley Hall)
- Saturday (tbc) in Nov, Birmingham
- Saturday 14 Nov, Wetherby

Choose a date and venue most convenient for you and book your place.

Please contact the Admin Team on 01604 611827 or email regionaladmins@btinternet.com

If you booked some time ago, and are waiting for information, please do chase us.

New research projects win funding

In October 2008 four new research projects were approved for funding by the Biomedical Research Advisory Panel (BRAP).

- A PhD studentship grant was awarded to Prof Chris Miller and Dr Kurt de Vos at the Institute of Psychiatry. In October 2009 a student will start work to join together two separate strands of MND research. They will link how damage to a gene known as 'VAPB' causes the accumulation of TDP-43 protein within motor neurones. In Spring 2008 researchers at the same institute showed that damage TDP-43 plays a role in causing MND. The grant is for £87,044 over three years.
 - Such is the success of an earlier PhD studentship grant, awarded to Dr Linda Greensmith and Dr Mike Cheetham at the Institute of Neurology, UCL, London, that the results generated could not be analysed in full by the student working on this project. The BRAP agreed to fund a supplementary project for 12 months costing £42,964. This will allow us to gain the maximum knowledge from this area of research - investigating a cellular defence mechanism that may help
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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

or post to:

Tricia Churchill
The Wellhouse
102 Christchurch Road
Winchester SO23 9TG

Useful Contacts

Branch Contacts

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Branch website : <http://www.mndsouthampton.org>

Donations to *Nalin Shukla, Treasurer, 5 Maytree Road, Chandlers Ford, SO53 5RT*

MND Association Contacts

Regional Care Development Adviser, South Central Region– Annemieke Fox – 0845 375 1831,
annemieke.fox@mndassociation.org

National Office – 01604 250505, enquiries@mndassociation.org

MND Connect – 08457 626262, mndconnect@mndassociation.org

MND Association website – www.mndassociation.org

Registered Office: Motor Neurone Disease Association, David Niven House, 10-15 Notre Dame Mews,
Northampton, NN1 2BG

Registered charity number 294354

MND
connect 08457 626262
mndconnect@mndassociation.org



Hampshire Neurological Alliance

Long Term Neurological Conditions: Improving Health and Social Care Support

The Maltings, Alton, Hants, GU34 1DT - 16 March 2009

Draft Program

- 9.30 Registration
- 10.00 Welcome by Councillor **Mrs F Hindson** (Executive Member, Hampshire County Council Adult Services)
- 10.05 Introduction - **Brian Eyre** (Chairman, Management Committee Hampshire Neurological Alliance)
- 10.10 **Session 1** Chair **Mrs R Trodd**
Experience of Living with Long term Neurological Condition
Panel of speakers representing from people directly affected
- **John Bailey** (carer- dementia)
 - **Liz McGowan** (MS)
 - **Barry Bullough** (Dystonia)
 - **Robert Whewell** (MND)
 - **Phyl Tappin** (Alzheimers Society)
- 10.50 Discussion
- 11.10 Coffee Break
- Session 2** Chair: **Dennis Morgan** (MS Society)
- 11.20 **Personalisation: Making it Happen**
Gill Duncan Director, Hampshire Adult Services, Hampshire County Council:
Questions and Discussion
- 12.00 Presentation: (Title to be advised)
Sue Damarell-Kewell Associate Director, Systems Management, Hampshire PCT
Questions and Discussion
- 12.45 Lunch and Networking
- 13.45 **Session 3** Chair **Brian Eyre**
Break out Discussion Groups: Four Groups led by HNA, Hants CC, Hants PCT
- HNA Leads: Annemieke Fox (MND Association) and Rikki Gandolph (Headway Association)
 - Hants CC Lead: Chandra McGowan
 - Hants PCT Lead: Nicola Howard
- Plenary: summary of conclusions
- 14.45 **Session 4** Chair: Brian Eyre
Status of Research into Long Term Neurological Conditions: Progress and Challenges
Professor A Thompson (Garfield Weston Professor of Clinical Neurology and Neurorehabilitation, Director of Institute of Neurology, University College London)
Questions and Discussion
- 15.45 **Closing remarks**
- 16.00 **Coffee and Networking**

Closing Date for registration: 7th March 2009

WORKING TOGETHER TO IMPROVE NEUROLOGY SERVICES

REGISTRATION FORM

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- Please reserve place/s for Working Together to Improve Neurology Services in Hampshire and the Isle of Wight.
 - Yes, I would like lunch, my dietary requirements are.....
 - My communication needs are.....
 - My access needs are.....
 - Any other specific needs.....
 - I have enclosed a cheque for £ which I understand is non-refundable in the event of my cancellation/non-attendance.

- | |
|---|
| <ul style="list-style-type: none">• The cost of this event for professionals is £10.• The event is free of charge to people with a Long Term Neurological Condition and their carers.• <u>Payment by cheque only please</u>, cheques should be made payable to <i>Hampshire Neurological Alliance</i>.• We regret that we cannot raise invoices, however, receipts will be provided upon request.• The fee is non-refundable, but booked places are transferable. |
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Name/s:

Job Title/s:

Address:.....

.....

.....

Email:..... Tel:.....

Please note that in order to reduce costs all correspondence will be via E-mail

Please advise us of any additional assistance needs you may have. If you are concerned with regards to transport costs or availability, please contact Lisa Goodridge directly to discuss your needs.

For directions to The Maltings please see www.altonmaltingscentre.com

Please return to:

Lisa Goodridge, Development Officer, The PSP Association, 167 Watling Street West, Towcester, NN12 6BX

Tel: 07902 305873 E-mail: lisa.goodridge@pspeur.org

Closing Date for registration: 7th March 2009
