



# *The News*

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**December 2006**

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### **Motor Neurone Disease Association**

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Email [enquiries@mndassociation.org](mailto:enquiries@mndassociation.org) Website [www.mndassociation.org](http://www.mndassociation.org)

Registered Charity No. 294354

## **Life Goes On**

The third poster in the Association's *Life Goes On* campaign, aimed at raising awareness of MND and the Association, goes live during December on the London Underground.

The third poster features Esther Camp, a 33-year-old mother from Basingstoke. The text says that after getting her diagnosis, Esther was found "with a needle in her arm". The accompanying image shows her getting a tattoo!

The photography for the third poster took place in a tattoo shop in Basingstoke in early November.

Esther met with photographers at *Area 51* where they pictured her having a tattoo. She was accompanied to the shoot by her Mum Pat and one of her carers.

Esther has been keen to be involved in the Life Goes On campaign, saying: "I'm delighted to be involved in the *Life Goes On* Campaign. I want to do everything I can to raise awareness of MND.

"It is important that people learn more about this devastating disease and support the MND Association who is working to find a cure."

You can find out more about Esther – and Rosie and Brian, the other faces of *Life Goes On* – on the Myspace online community. If you have your own Myspace page, you could "make friends" with all three of them, and invite the rest of your network to do the same.

To find out more, simply go to: [www.myspace.com/lifegoesonbrian](http://www.myspace.com/lifegoesonbrian)  
[www.myspace.com/lifegoesonrosie](http://www.myspace.com/lifegoesonrosie)  
[www.myspace.com/lifegoesonesther](http://www.myspace.com/lifegoesonesther)

You can also find out more about the Life Goes On campaign at [www.lifegoeson.org](http://www.lifegoeson.org).

**Sarah Fitzgerald**

**Head of PR & Media**

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## **TV show seeks participants**

The makers of the popular Channel 4 show *Wife Swap* are looking to feature a family where either the mum or dad is affected by disability. The premise of the show is that the mums from two families are swapped to experience a different way of living. Rachael Stubbins from RDF Television said: "We're currently making a new series and we're taking the programme back to its documentary roots, looking in an

observational way at family life in the UK and celebrating different lifestyles in modern Britain.”

Families interested in taking part should contact Rachael Stubbins. You can either email her at: [Rachael.stubbins@rdfmedia.com](mailto:Rachael.stubbins@rdfmedia.com) or call her on 0207 0134514.

**Louise Carter**

**PR & Media Officer**

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## **PUBLIC AFFAIRS**

### **All-Party Group meeting**

A big thank you to all the Branches and Groups who have let me know their local MPs have said they are coming to the next meeting of the All-Party Parliamentary Group on MND.

The meeting is being held on 6 December so if you're reading this before then and you haven't told me your MPs are coming please let me know! This is important if the meeting is cancelled or the room changes.

I'll let you know how the meeting went in the next edition of *The News*.

**Alison Railton**

**Public Affairs Manager (Job Share)**

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## **National Voices**

National Voices is being organised by the LMCA, the umbrella body for national voluntary organisations working to meet the needs of people with long-term health conditions, as a potential new way to consult over health policy.

Its basic function is to provide a mechanism for existing voices to come together for greater effect on policymaking at national level.

**Features:** It will create a network of national not-for-profit organisations that champion the interests of service users, patients and carers and will give them a complementary, co-ordinated voice.

It will operate in England, it will have charitable status, membership will be open to national organisations in the first instance but could perhaps open up to local organisations and individuals in future. It will in part be funded by its members and in part funded by the Department of Health and other stakeholders.

**Benefits** include a strengthened voice, a systematic and consistent approach to involvement in policy development on cross cutting issues and greater influence on

policy and access to more frequent and better quality opportunities to engage with Government.

The LMCA is consulting on this and we will be responding.

**Mark Hill**

**Public Affairs Manager (Job Share)**

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## **CONFERENCES**

### **International Symposium**

By the time you read this the 17<sup>th</sup> International Symposium on ALS/MND will have been held in Yokohama, Japan.

We are expecting more than 600 delegates from across the world, including Europe, the United States, Australia and a large Asian contingency.

We will report back on the symposium in the next edition of *The News*.

### **Spring Conference 2007**

These one-day gatherings are primarily for people living with MND and their carers. Everyone with an interest in MND is welcome.

The following dates and venues are now confirmed:

14 April – Hilton, Belfast

28 April – Hilton, Blackpool

29 April – The Majestic Hotel, Harrogate

12 May – The Paramount Hotel, Oxford

13 May – Hilton, Newport

20 May – The Hampshire Centre Court, Basingstoke

Copies of a flyer advertising our Spring Conferences are available to download on our website, [www.mndassociation.org/events](http://www.mndassociation.org/events) and visit the Spring Conferences section. Alternatively contact Ros Norris on 01604 611826.

### **AGM/Annual Meeting 2007:**

15/16 September – Hilton Birmingham Metropole

Full details on all of these events, and registration, will appear on our website as they become available. Please contact me for further information.

**Kim De Lancey**

**Conference Assistant**

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# CARE DEVELOPMENT (includes Care Services, Regional and Volunteering Teams)

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## **The Work & Families Act**

The Department of Trade and Industry (DTI) has announced the definition of carers that will be used in the Work and Families Act.

The Act gives carers a groundbreaking new right to request flexible working from their employer and comes into effect in April 2007.

For more information contact Carers UK. Telephone CarersLine: 0808 808 7777. Email: [info@carersuk.org](mailto:info@carersuk.org) Website: [www.carersuk.org](http://www.carersuk.org)

Alternatively contact the MND Association Helpline for further information. Telephone 08457 626262.

Email [helpline@mndassociation.org](mailto:helpline@mndassociation.org)

(Please note this information may not apply in Wales and Northern Ireland. Please contact [www.carerswales.org](http://www.carerswales.org) , 029 2081 1370 or, [www.carersni.org](http://www.carersni.org) on 028 9043 9843.)

## **The Council Tax Reduction Scheme**

The Council Tax reduction scheme is funded by your local authority. Individuals can get a reduction if they or any other resident in their household *is substantially and permanently disabled*. They must meet at least one of the three following conditions: -

- have an additional bathroom or kitchen needed by the disabled person
- have a room (other than a bathroom kitchen or toilet) needed by & predominately used by that person
- have enough space in that dwelling to use a wheelchair indoors

Individuals entitled to a reduction will have their council tax reduced to the next band down. Those already on the lowest band, will receive a reduction by one sixth. Contact your local council for an application form.

Alternatively contact the MND Association Helpline for further information on 08457 626262. Email [helpline@mndassociation.org](mailto:helpline@mndassociation.org)

(Please note this information may not apply in Wales and Northern Ireland. Please check with your local council).

## **What is Doctor Babel?**

This new website [www.doctorbabel.com](http://www.doctorbabel.com) enables individuals to create a simple medical record online that can be translated accurately into many languages. This is good news for people living with MND planning a trip overseas.

Individuals can record their condition along with their medication and other medical details.

They can then translate this into any of a number of languages by simply selecting the relevant language and pressing 'translate'. They can then print the record and take it on their trip.

The usual cost for this service is £20, but if people living with MND follow the link from the MND Association website, they will get an automatic discount of £2.  
[www.mndassociation.org](http://www.mndassociation.org)

**Sharon Schillerstrom**

**Care Information Resources Manager**

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### **Message in a Bottle Scheme**

The Lions 'Message in a Bottle' scheme is a simple idea designed to encourage people to keep their personal and medical details on a standard form and in a common location - the fridge. Bottles are free of charge and can usually be found in your local chemist or doctors' surgeries.

You may also find you can obtain one through your nearest Neighbourhood Watch group, Age Concern, Council Offices, Housing Associations and other places including Police stations.

If you have difficulty finding a bottle, please contact Lions International. Telephone: 0845 833 9502. Email: [miab@lions.org.uk](mailto:miab@lions.org.uk)

Website: [www.lions.org.uk](http://www.lions.org.uk) Or contact the MND Association Helpline for further information. Telephone 08457 626262. Email [helpline@mndassociation.org](mailto:helpline@mndassociation.org)

**Jacqui Roughton**

**Care Information Adviser**

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### **Learning from our experiences**

At a recent event, members of Northants Branch experienced two disturbing episodes that we have been asked to bring to the attention of all other Branches.

The main money-spinner was a tombola, the items placed on one table at the front and others at the back of the gazebo.

Shortly after opening a lad aged around 13 bought a number of tickets and after failing to win declared that he wanted a cheese board because the package contained a knife. Fortunately his money ran out before we were faced with a difficult decision and possible trouble. Another around the same age who tried to win a gardening kit because it contained a large pair of scissors followed this lad. At this point we suspended trading and searched all items for anything that could be used as an offensive weapon.

The second episode involved a group of five girls one of whom kept the attention of the member with the tickets while the others caused chaos by handling items on the stall, refusing things they had won and trying to change them for others.

There were three of us on the stall but with a large frontage it was necessary for one to be at the other end selling cakes, crafts etc. She called two community policemen who moved the girls on. We then discovered that four items were missing from the stall.

Maybe we have been too naïve in the past but hope to have learned from this experience. We now vet everything offered for sale, keep the items at the back of the stall and try to make sure that there are always four people at any one time.

### ***Northants Branch***



#### **Spotlight on: Branch meetings**



The Lincolnshire Branch covers a huge area and our members may travel up to 45 miles to our monthly Branch meetings which alternate between Boston and Lincoln.

It is therefore very important that we make our meetings interesting to make it a worthwhile trip.

Our Christmas and summer lunches are always well attended but finding a venue with adequate disabled toilet facilities is often a challenge. Although pubs and restaurants are obliged to have disabled facilities, the reality is that they are often inadequate for a person with MND in a wheelchair. On several occasions we have had the embarrassment of trying to extricate a member from the ladies loo which has no more than a grab handle to meet the requirement of the law. A prior visit is therefore essential before booking.

With around 30 people attending the lunches, we can usually negotiate a fixed price for the meal and arrange for any special dietary requirements.

The family run pubs are excellent value with the bigger pub chains a poor second – the only advantage being a better standard of loo. We do not charge for people with MND and carers but provide a subsidy from Branch funds to cover the cost. A raffle usually raises £50 so the net cost is never more than £50 and often less.

Finding speakers is never easy but a list of speakers provided by radio Lincolnshire is a good starting point. Most charge a fee between £20-£30 (usually in the form of a donation to another charity) but this expenditure is considered an essential element if meetings are to be interesting and worthwhile. We are very fortunate in having our own guest speaker who we can call upon at short notice to “fill-in”. When his wife was diagnosed with MND, they elected to travel the world to some of the most inaccessible parts of the planet – slides taken on their travels are breathtaking.

For our meeting this September we decided to be more ambitious and organise a four-hour boat trip up river from Boston to Tattershall and return. We arranged it in the school holidays so that children and members families could enjoy a day out as a “thank you” for all the hard work people had put in during the summer. We had 44 folk on board which included four people in wheelchairs and two members of the NHS

Outreach team. We subsidised the trip which cost £480 to hire the boat and to provide lunch on board. The weather was perfect and the trip brilliantly successful.

To our surprise we actually broke even as we received several unexpected donations, including £50 from a new member who passed on his fee for his appearance in a TV series The Way We Were.

Finally to those who may be thinking of organising a boat trip – do check the loos before your voyage and don't take the boat owner's word that they have a disabled toilet –you could have one of your members wedged, in nautical terms, in the men's heads!

### ***Lincolnshire Branch***

***Wendy Crofts***

***Volunteering Development Manager***

[Wendy.crofts@mndassociation.com](mailto:Wendy.crofts@mndassociation.com)

DDI: 01604 611823



### **2007 Association Visitor Programme**

We are in the process of printing the new Association Visitor Programme for 2007 including dates and locations of the forthcoming training courses.

These training courses prepare volunteers to provide an informed and supportive visiting and befriending service to people with MND and their carers.

Did you know the Association won a National Training Award in 2004 for their high quality and excellence in it visitor training?

### **Association Visitor Training Course Dates for 2007:**

#### **West Midlands**

Thursday, 18 January 2007

Friday/Saturday, 2/3 February 2007

Tuesday, 27 March 2007

#### **West of England**

Thursday, 19 April 2007

Friday/Saturday, 11/12 May 2007

Wednesday, 27 June 2007

#### **Central**

Tuesday, 1 May 2007

Friday/Saturday, 18/19 May 2007

Saturday, 7 July 2007

#### **North East**

Thursday, 13 September 2007

Friday/Saturday, 21/22 October 2007

Thursday, 15 November 2007

**London**

Saturday, 13 October 2007

Saturday/Sunday, 3/4 November 2007

Saturday, 8 December 2007

If you are interested in attending one of these courses or would like more information about becoming an Association Visitor please contact one of us.

***Anneka Minter/Tracey Lucas-Apea***

***Recruitment and Training***

***Co-ordinators***

[Anneka.minter@mndassociation.org](mailto:Anneka.minter@mndassociation.org)

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## ITEMS FOR SALE

The MND Association offers a free advertising service, but we cannot accept responsibility for the condition of the items advertised. All arrangements for collection of items for sale should be made directly between buyer and seller in all instances.

Where specialised or lifting equipment is concerned, you are strongly advised to seek advice from your Occupational Therapist and the manufacturer as to suitability and health and safety requirements.

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**Details:** Two Possums HC 1800 Companion. Instructions included. Four years old and in good working order.  
**Asking price:** £4,000 o.n.o. for the two  
**Area:** Guernsey  
**Contact:** Derek  
**Tel:** 01481 257519

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**Details:** Through-Floor lift. "Terry" full lift. Manual or remote control. Will take any wheelchair. Has been de-installed and left intact  
**Asking price:**  
**Area:** Shrewsbury  
**Contact:** Alwyn Morgan  
**Tel:** 01743 242638

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**Details:** Converted car. 2003 Renault Kangoo. 1.2 16v, five doors (sliding rear side doors). 12,500 miles approx. Professionally modified by Gowing Mobility. Rear platform access for a wheelchair. Three passenger seats including one alongside wheelchair  
**Asking price:** Offers over £6,500  
**Area:** Oxford  
**Contact:** Mrs Dick  
**Tel:** 01865 862978 or 0771 3742285

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**Details:** Wheelchair TGA Powerpack Series 4. Includes all fittings and battery. Complete with handbook. Used less than 12 times. Cost £600 new  
**Asking price:** £300  
**Area:** West Yorkshire  
**Contact:** Barbara Fawcett  
**Tel:** 01274 869123

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**Details:** "Go Go" four-wheel travel scooter. Quickly disassembles into four pieces. The heaviest piece weighs 13kg. As new – two years old. Only used for four months.  
**Asking price:** £500 o.n.o  
**Area:** Derby  
**Contact:** Mrs Maureen Hargreaves  
**Tel:** 01332 515917

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**Details:** "Brigayd" electric car wheelchair hoist. Takes up to 100kg in weight. Includes a spreader bar and safety restraint. Only used six times. Cost £1,350, including fitting. Easily removed.

**Asking price:** Offers requested (monies will be donated to The Association)

**Area:** East Sussex

**Contact:** Janet Denny

**Tel:** 01797 223389 or 07962 930912 (Mobile)

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# FUNDRAISING

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## COMMUNITY FUNDRAISING

### **'Message in a Bauble'...**

December is now upon us and the jolly festive season is just around the corner. The Christmas lights are already turned on and well organised people will already have their Christmas cards written out and soon the postman will be dropping them through our doors.

A large firm of solicitors with Branches throughout Suffolk are supporting us this year with this excellent way of making effective use of Christmas to provide support. This is brilliant news! This all came about from a conversation with one of the Community Fundraising team so mention it to everyone you speak to because you never know who might help!

Please make sure you have also ordered your posters so your friends, family and colleagues are able to buy a bauble instead of a card and thus provide some Christmas cheer for all by knowing that their donation will help people with MND.

***Denise Davies, Elaine Wyspianski, Sally Harding and Anita Frith***

***Community Fundraising Team***

[fundraising@mndassociation.org](mailto:fundraising@mndassociation.org)

Direct Dial: 01604 611860



### **'Into the deep blue sea!'**

They did it!

Many congratulations go to our valiant team of 'Swimtrekkers'!

Their re-location in Croatia proved to be a real hit with team and the unexpected glorious weather, certainly helped combat the rather chilly and bracing ocean.

The pretty island of 'Zlarin' became 'base camp' for the week, and a welcome place to rest weary heads after a hard day's work.

The first of the five-day challenge, was literally in at the deep end! The strong winds prevailed, resulting in a significant 'chop' to recon with.

Three miles into these conditions, and one or two began to wonder what they had let themselves in for...and even considered the prospect of being hauled out, and into the support boat. Sheer will power, focus and determination ensured all successfully landed!

Thankfully, the sea conditions improved as the week went on, and their confidence and ability grew to new heights.

Camaraderie and team spirit was essential, and resulted in a 'very special' event with many a story to tell...and many a memory to treasure.

This particular challenge event did not only require a high degree of physical ability, but also a great deal of courage and psychological strength.

I take my hat off to all of the team...they were amazing, and this fundraiser is very proud of you! Mission accomplished...

***Elaine Wyspianski***

***Community Fundraiser***

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Direct Dial: 01604 611866



### **Time to D'Feat MND**

Well done everyone.....!

The clocks have gone back, the long nights are drawing in and the Time to D'Feat MND Tea Parties have, by and large, happened.

Congratulations to all who took part and made this new national event such an incredible success in its first year.

There have been over 40 fabulous Tea Parties around the country each raising between £300 and £2,500 which is a tremendous result.

From the income received to date from about a quarter of the registered events we have raised around £10,000 already.

We have received some lovely pictures from the parties of gorgeous cakes, lots of people wearing funny hats and generally fun being had by all. Many thanks for sending those to me.

I was also pleased to be able to attend a few parties myself to get a first hand view of the feel of the event. I have thoroughly enjoyed meeting some of you and partaking of wonderful cream teas and joining in the fun and games.

If there are any of you out there who have held Tea Parties under the general theme of this event but decided not to register it with us please do let us know how it went and how much it raised for your Branch as it will help us to assess the overall success of Time to D'Feat for the future.

Also if you have any great pictures we would love to see them!

***Sally-Ann Harding***

***Senior Community Fundraiser***

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## **CORPORATE DEVELOPMENT**

### **Collect old phones and increase your Branch/Group Income!**

Each year new advances are made in mobile phone technology and as a result millions of new mobiles are purchased and old ones discarded – especially around Christmas time!

Eventually many of these will be thrown away and end their days in landfill sites where they can release harmful substances into the earth. A whole new industry has grown up around collecting and recycling old mobiles: that's very good news for the Association and for the environment.

By asking everyone to donate their redundant mobile phones to the MND Association you can generate valuable funds. For every mobile donated via your Branch or Group *you will be credited with £3* which is the full amount paid to the Association. The mechanics of the scheme could not be simpler. The donor of the phone removes the SIM card, pops it into one of our freepost envelopes and posts it in the usual way.

We know that there are literally millions of redundant mobile phones lying idle – please help us to unlock this valuable source of income for the MND Association by seeking these out from:-

**colleagues ~ friends ~ family ~ pubs ~ rotary clubs ~ businesses ~ sports clubs ~ youth groups ~ your own homes!**

To take part in this great fundraising scheme please email [corporate@mndassociation.org](mailto:corporate@mndassociation.org) or call the Corporate Team on 01604 611888.

### **VSG Month for Running**

#### **February 2007**

The national security company VSG is raising £50,000 for the MND Association, and is their largest corporate sponsor for 2007.

To help get all VSG's 3,000 staff involved in their fundraising efforts, VSG have committed February as **VSG month for Running!** To make this happen, the VSG Charity Team have been busy researching running events up and down the country ranging from 5km short runs right up to half marathons.

If you would like to become involved in the VSG Month for Running please view the list of events below and contact the VSG Communications Department for further details.

#### **MIDLANDS**

Wellingborough Multiterrain 5, 10 and 15km

#### **SOUTH WEST**

Puma Longleat 10km

#### **WALES**

Cardiff Valentines 10km

#### **SCOTLAND**

RAF Kinloss Lossiemouth ½ Marathon

#### **SOUTH**

Chichester Priory 10km

#### **EAST**

Ryston Grand Prix 5km  
**NORTH WEST**  
Blackburn "Winter Warmer" 10km  
**NORTH**  
Dewsbury Classic 10km

Together we can make a difference!

For further information please contact Oliver at VSG on 0845 838 7630  
fundraising@vsg.co.uk  
www.vsg.co.uk/fundraising

**Madeleine Collins**  
**Corporate Development Support Officer**  
[madeleine.collins@mndassociation.org](mailto:madeleine.collins@mndassociation.org)  
Direct Dial: 01604 611832



## **SUPPORTER DEVELOPMENT**

### **Free membership for volunteers**

The vital work of the MND Association is only possible because of the dedication, passion and hard work of our volunteers, particularly those who serve on Branch and Group Committees, and as Association Visitors.

The Board of Trustees felt it was time that this amazing contribution was properly recognised. And so, at the AGM in September, a change in our constitution was proposed and passed to WAIVE MEMBERSHIP FEES for those volunteers who serve in a formally-recognised role.

A "formally-recognised role" applies to volunteers who serve as a Branch Committee member, or who play a comparable role on a Group, or are an Association Visitor.

Please notify Sarah Mayes on 01604 611825 of any new volunteers in these roles, so that we can include them in this programme too.

We will be writing to everyone who is entitled to free membership over the coming 12 months, as their memberships come up for renewal.

If you would like more information on this, please call our Membership Team on 01604 611855, or e-mail [membership@mndassociation.org](mailto:membership@mndassociation.org)

**John Blake**  
**Head of Supporter Development**  
[john.blake@mndassociation.org](mailto:john.blake@mndassociation.org)  
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## **MAJOR DONORS**

### **A Valuable Meeting**

Myself and the Association's Director of Fundraising, Malcolm Tyndall, met Terry Waite at a recent Third Sector Forum.

We collared him for a Thumbprint Christmas Ball auction prize, which he agreed to!



Photo: Chris Wood of Chris Wood Studios

***Veronica Martin***

***Head of Major Donors***

[Veronica.martin@mndassociation.org](mailto:Veronica.martin@mndassociation.org)

## **Research projects on the web**

Details of all the research projects currently funded by the Association can now be found on our website. Each project has its own page giving a simple overview of the project's ultimate aims as well as a more detailed description of the science.

These pages are aimed at people affected by MND who want to keep up with the latest research activities and donors wanting to know how their money might be spent.

The new pages can be found by following the "Research We Fund" link in the Research section.



## **New projects approved for funding**

Following the Research Advisory Panel meeting in October, two new studentship projects have now been approved for funding:

- Dr Sharon Abrahams and Dr Thomas Bak from the University of Edinburgh will supervise a project taking an in-depth look at cognitive function in ALS.
- Dr Gennadij Raivich and Dr Axel Behrens of University College London will build on preliminary work suggesting that switching off a certain gene can slow disease progression in mice that model MND. Exploring the mechanisms underlying this effect could lead to the development of potential treatments.

• The Association will also be contributing to an exciting project called a "Whole Genome Scan" that will use new technology to look for gene variations that contribute to the development of MND. This project, led by Dr Ammar Al-Chalabi of King's College London and Prof Bob Brown of Harvard Medical School, will be the first to use samples from the Association's DNA Bank.

More details on these projects will be published on the web pages mentioned above and in the next revision of Research Information Sheet E, "Funding MND Research".

## **The next round...**

We received 27 summary applications for the inaugural Research Foundation application round; 21 of these have been invited to proceed to the full application stage. Watch this space in spring to find out which projects are approved for funding.



## **Research Advisory Panel changes**

*Goodbye and thanks to...* Prof Roy Quinlan, Dr Orla Hardiman and Prof Michael Sendtner, who stepped down as panel members after the last meeting. We are very grateful for their input over the last four years.

*Welcome to...* Dr Caterina Bendotti from the Department of Neuroscience at the Mario Negri Institute in Milan; Dr Kevin Talbot, director of the MND Care Centre at

the Radcliffe Infirmary, Oxford; Prof Wim Robberecht from the Department of Neurology at Leuven University Hospital in Belgium.



**International Symposium news**

By the time you read this, the 17<sup>th</sup> International Symposium on ALS/MND will have finished. You can still read all the daily bulletins and online diaries on the My Symposium website: log on to [www.mndassociation.org/mysymposium](http://www.mndassociation.org/mysymposium)

***Kate Arkell***

***Research Information Co-ordinator***

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Direct line: 01604 611806

**BRANCH/NATIONAL FUNDRAISING EVENTS DIARY**

<b>DATE</b>	<b>BRANCH / EVENT</b>	<b>CONTACT NAME / TEL NO</b>	
2-9 December	Christmas Tree Festival, Dartford Methodist Church, Spital Street, Dartford	Eileen Finlay	01322 228169
31 December	'New Year's Eve Dance' 8pm into New Year, Village Hall, Cranleigh, Nr Guildford Surrey. Live Band – Dancing to JL Sound	Sallie Bushen	01483 274337
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26 January 2007	Post Christmas Sale, Sherborne St John Hall, near Basingstoke	Chris Parsons	01256 359790
27 January 2007	Performance Collection 'Fiddler on the Roof' Basingstoke Operatic Society, Haymarket Theatre, Basingstoke	Chris Parsons	01256 359790
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21 May 2007	Plant Sale, Frogmore Green Hall, near Blackwater	Chris Parsons	01256 359790

## SERVICES CONTACT SHEET December 2006

When telephoning National Office, please dial 01604 611 followed by the extension number listed after the name. Eg: to telephone Christine Morton dial 01604 611841.

If on ringing the extension you hear the voicemail+ message, but you would still like to talk to one or two other people at National Office, then you can press 1 and the other person's extension number.

<b>Subject</b>	<b>Service Contact</b>
BENEFITS	Care Information Service <b>870</b>
BRANCH ADVICE (General)	Sarah Mayes <b>825</b>
BRANCH ADVICE (Regional)	
<b>Northern</b> Regional Manager	Steve Bell <b>08453 751820</b>
Northern Regional Office	Loraine Webster <b>01274 620309</b>
VDC - North East	Chris Oakenfull <b>08453 751845</b>
VDC - North West	Karen Hickmore <b>08453 751833</b>
<b>Central</b> Regional Manager	Michelle Hodson-Curran* <b>08453 751830</b>
VDC - West Midlands & Wales	Angela Lea <b>08453 751834</b>
VDC Central / East Midlands & Anglia	Ruth Clark <b>08453 751829</b>
<b>Southern</b> Regional Manager	Mike McKeivitt <b>08453 751840</b>
VDC -South Central / S West	Su Starkey <b>08453 751839</b>
VDC -South East	Stefanie Cormack <b>08453 751848</b>
BRANCH FUNDRAISING SUPPLIES	Ros Norris <b>826</b>
BRANCH MAILINGS (inc <i>The News</i> )	Sarah Mayes <b>825</b>
BREATHING SPACE KITS	Care Information Service <b>870</b>
CAMPAIGNING	Alison Railton <b>842</b> / Mark Hill <b>844</b>
	Julie Compton <b>0115 9858346</b> (Central Region only)
CARE DEVELOPMENT (General)	Julie Lavender <b>874</b> / Heidi Macleod <b>871</b>
CARE ISSUES & ADVICE:	
National Office	Care Information Service <b>870</b>
Regional	RCAs - see over for listing
CARE CENTRE PROGRAMME	Debra Garside (programme head) <b>08453 751843</b>
CHRISTMAS AND SPRING CATALOGUES	Ros Norris <b>826</b> / Sarah Mayes <b>825</b>
CLINICAL TRIALS	Belinda Cupid <b>847</b> / Marion Reichle <b>849</b> / Brian Dickie <b>848</b>
CONFERENCES	Pam Aston <b>845</b> / Kim De Lancey <b>822</b>
DESPATCH	Kay Attard <b>818</b> / Mick Paine <b>811</b>
DIARY OF EVENTS	Ros Norris <b>826</b>
EQUIPMENT FOR DISABILITY	Care Information Service <b>870</b>
EQUIPMENT LOAN	Equipment Loan Service <b>802</b>
FINANCIAL SUPPORT	Jane Skelton <b>876</b> / Heidi Macleod <b>871</b>
FINANCE & BRANCH ACCOUNTS	Colin Byer <b>808</b> / Teresa Morrisroe <b>856</b>
FUNDRAISING	<b>860</b>
Affinity Credit Card	John Blake <b>835</b>
Appeals	Tracey Walton <b>862</b> / John Blake <b>835</b> / Angeles Garcia <b>862</b>
Branch Fundraising	Denise Davies <b>833</b> / Elaine Wyspianski <b>866</b> / Anita Frith <b>867</b>
Community Fundraising	Denise Davies <b>833</b> / Elaine Wyspianski <b>866</b> / Anita Frith <b>867</b>
Corporate Development	Mandy Lomax <b>864</b> / Madie Collins <b>832</b> / Derek Thorpe <b>01242 573980</b>
In Memoriam Donations	Esther Fifield <b>881</b> / Shabz Khokhar <b>830</b>
Legacies	Stephen May <b>865</b>
Lottery	Malcolm Tyndall <b>836</b>
Marathon	Elaine Wyspianski <b>866</b> / Anita Frith <b>867</b>
Raffles	Elaine Wyspianski <b>866</b> / <b>833</b>
Tax Effective Giving / Gift Aid	John Brownsell <b>883</b>
Trusts	Leanne Dines <b>861</b>
	Nicola Wilkinson / Janet Lee (Voicemail) <b>828</b>
GRANTS: Research	Marion Reichle <b>849</b> / Belinda Cupid <b>847</b> / Brian Dickie <b>848</b> / Kate Arkell <b>806</b>
HELPLINE	Care Information Service <b>870</b>

**14:40+voicemail is a personal answerphone system allowing the caller to leave a message directly with the person they are trying to reach, but who is currently away from their desk**

HR RECRUITMENT	Kay Attard <b>818</b>
INFORMATION PACKS	Care Information Service <b>870</b>
INSURANCE	Colin Byer <b>808</b>
LEAFLETS ON MND	Care Information Service <b>870</b>
LIBRARY	Sheila Lloyd <b>838</b>
MEMBERSHIP	Kay Gibson <b>855</b>
MND WEEK	Sarah Fitzgerald <b>840</b>
PAYROLL GIVING	Mandy Lomax <b>864</b>
PERSONNEL	Kay Attard <b>818</b>
PRESS/PUBLICITY/PR	Sarah Fitzgerald <b>840</b> / Louise Carter <b>843</b> / Richard Green <b>837</b>
PUBLIC AFFAIRS	Alison Railton <b>842</b> / Mark Hill <b>844</b> / Richard Green <b>837</b>
PUBLICATIONS	
Annual Review	Christine Morton <b>841</b>
Thumb Print	Christine Morton <b>841</b>
The News	Paula McGrath <b>877</b> / Christine Morton <b>841</b>
Care literature (patients and professionals)	Care Information Service <b>870</b>
RESEARCH	Marion Reichle <b>849</b> / Belinda Cupid <b>847</b> / Brian Dickie <b>848</b> / Kate Arkell <b>806</b>
TRIBUTE FUNDS	Stephen May <b>865</b> / Kay Gibson <b>855</b>
VAT	Malcolm Watkins <b>814</b> / Colin Byer <b>808</b>
VISUAL IDENTITY (logo etc)	Christine Morton <b>841</b>
VOLUNTEERING	Jools Cook <b>01691 662303</b>
VOLUNTEER TRAINING	Elinor Brien <b>824</b>
VOLUNTEER RECRUITMENT	See relevant VDC

**CARE ISSUES & ADVICE (Regional Care Advisers) RCAs**

**Telephone**

**Northern Region**

North	Hilary Shaw	<b>08453 751837</b>
North East / Central Yorkshire	Sue Smith	<b>08453 751822</b>
North West	Anna Conlan	<b>08453 751841</b>
Greater Manchester	Pat Ridgway	<b>08453 751835</b>
Mersey	Kathy James	<b>08453 751832</b>
North Trent	Jane Evans	<b>08453 751821</b>
Northern Ireland	Helen McClean	<b>08453 751852</b>

**Central Region**

West Midlands (North)	Jacqueline Dornford-May	<b>08453 751842</b>
West Midlands (South)	Jo Deakin	<b>08453 751846</b>
East Anglia	Liz Cooper	<b>08453 751827</b>
Central	Moira Mosley	<b>08453 751854</b>
Trent	Jane Connell	<b>08453 751836</b>
North Wales	Kevin Thomas	<b>08453 751824</b>
South Wales	Carol Thomas-Wyllie**	<b>08453 751853</b>

**Southern Region**

South Central	Karen Wetherick	<b>08453 751831</b>
West of England	Hilary Fairfield	<b>08453 751828</b>
South West	Bill Nevin	<b>08453 751844</b>
North West Thames	Liz Garrod	<b>08453 751826</b>
North East Thames	Frances Carroll	<b>08453 751851</b>
Surrey & Sussex	Kate Pottinger	<b>08453 751825</b>
South East Thames	Nyree Clark	<b>08453 751849</b>
South West and West London	Angie Coster (temp)	<b>08453 751847</b>

All National Office staff and all regional staff, RCAs and VDCs, can also be contacted by email.

The address to use is: [given\\_name.surname@mndassociation.org](mailto:given_name.surname@mndassociation.org). eg.

[christine.morton@mndassociation.org](mailto:christine.morton@mndassociation.org) \* Email address is [michelle.hodson@mndassociation.org](mailto:michelle.hodson@mndassociation.org)

\*\* Email address is [carol.thomaswyllie@mndassociation.org](mailto:carol.thomaswyllie@mndassociation.org)