

The News

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November 2006

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Motor Neurone Disease Association

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Registered Charity No. 294354

C **COMMUNICATIONS**

PR & MEDIA

MND on TV and radio

October was an incredibly busy and productive month for the MND Association's awareness-raising efforts. We were involved directly and indirectly in a number of TV and radio broadcasts, all aimed at raising the profile of MND and getting over the message about what can be done to improve care and research.

This was great news for the launch of our new Life Goes On campaign, which itself gained coverage in the London print media.

Here are some examples of the TV and radio coverage of MND during the month:

MND was featured in BBC1's *Holby City*, with the major storyline about Gina Hope reaching its conclusion – episodes were broadcast on 3, 10 and 17 October, each attracting around seven million viewers.

Gillian Bevan, the actress who played Gina Hope in *Holby*, appeared on *BBC Breakfast News* to talk about MND on Monday, 16 October.

Gillian was also just one of the guests who took part in a whole day of MND-themed programming on *BBC Radio Five Live* on Monday, 16 October. The day centred around Ned Cullen, who has MND, and his wife Heather, talking about their experiences of the disease. On hand to give their views were also: Dr Kirstine Knox, our Chief Executive, the Duchess of York, our patron, Prof Chris Shaw from King's

College Hospital and Dr Kevin Talbot from the Oxford Care Centre.

On Friday, 13 October, Gillian and Kirstine took part in more than 20 radio interviews, to talk about the MND Association's campaign for greater access to non-invasive ventilation (NIV). This included Radio 4's *You and Yours* programme, which was due to broadcast its coverage of this issue on Thursday, 19 October.

Paul Bradley, who plays Elliot Hope in *Holby*, was interviewed about the MND storyline on ITV's *GMTV* on Tuesday, 17 October, with our name and helpline number featured throughout.

And finally . . . Denise Welsh, patron of the Manchester Branch, appeared on ITV's *Loose Women* wearing her MND wristband!

This is all great news as we work to push up our public awareness levels still further. Branches and Groups are continually doing their own bit to help raise awareness locally, and there is no doubt this is also contributing to our current record awareness levels.

Sarah Fitzgerald

Head of PR & Media

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Direct Dial: 01604 611840



PUBLIC AFFAIRS

Parliamentary reception

As *The News* went to press we were due to hold our first ever Parliamentary reception. I'll report back on how it went in the next edition of *The News*.

All-Party Group meeting

The next meeting of the All-Party Parliamentary Group on MND will be held on 6 December. Dr Chris Clough will be speaking on the National Service Framework (NSF) for Long-term (Neurological) Conditions and the Findlay family will be talking about their personal experiences of MND. I have written to all Branch/Group Secretaries asking them to encourage their local MPs to attend the meeting.

Alison Railton

Public Affairs Manager (Job Share)

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Direct Dial: 01604 611842

Continuing Care

We have recently responded to a Government consultation on continuing care.

We feel it meets the needs of people with MND well. The document seems to indicate that people with MND will be given a high priority when assessing their continuing care needs.

We welcome in principle the proposal that assessors will be able to be flexible with the guidelines. However we are concerned that this could create anomalies for people living with MND, if different assessors have different interpretations of the disease. We hope having national rather than local guidelines will help solve this problem. Reference throughout the document is made to fast-tracking the provision of continuing care for those whose health is deteriorating quickly with a rapidly-progressing condition, and who have a short life expectancy. MND should be explicitly included in that category.

Mark Hill

Public Affairs Manager (Job Share)

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CONFERENCES

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 venues have been selected to give delegates the opportunity incorporate the conference into a weekend break. This year's dates are:

15 April – Venue TBC, N Ireland

28 April – Hilton, Blackpool

29 April – Majestic Hotel, Harrogate

12 May – Paramount Hotel, Oxford

13 May – TBC, Wales

20 May – Centrecourt, Basingstoke

The Spring Conference flyer enclosed with *The News* can be downloaded from our website or, for hard copies, contact Ros Norris in Volunteering, on 01604 611826 or email volunteering@mndassociation.org

Other conference dates:

Health and Social Care

Professionals' Study Day 2007:

27 June – Hilton Birmingham Metropole

AGM/Annual Meeting 2007:

15/16 September – Hilton Birmingham Metropole

International Symposium 2007:

1-3 December – Westin Harbour Castle, Toronto, Canada

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

Kim.delancey@mndassociation.org

Direct Dial: 01604 611822 or 611845

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

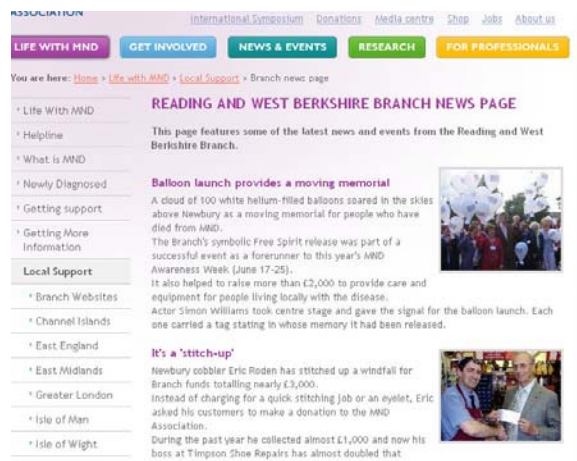
New On-line News Page to help you make the first step

If you have thought about a website but it's not possible to start developing one just yet, then this might be your solution for the shorter-term.

The on-line news page is a new facility on the main Association website, where your Branch or Group can have a web page to talk about recent activities and publicise them more widely.

What would it look like?

The page would be dedicated to your Branch or Group, with space for short paragraphs on two or three recent events (fundraising, awareness raising, successful get-togethers) and photos. Here's an example of how it could look:



How does it work?

The first step is to talk to your team or committee and think about who would be willing to be the contact for the on-line news page. They would be willing to draft the news page and liaise with National Office, both about getting it up and running and keeping it up-to-date.

The contact would also need to be proactive about contacting National

Office with updates and photos. The idea is to keep the pages looking fresh, so any new event would be added at the top, and an old one deleted from the bottom on an on-going basis.

As the pages are part of the main site, it's important to be aware we will need to edit the text and ensure the page fits in with the corporate identity guidelines.

Contact us for more information

Once you've had a think about it, contact Ros Norris on 01604 611826 or via ros.norris@mndassociation.org for more information.

New-look website templates and guidelines

Thanks to the webmaster of the E London Group, Kevin Joyce, and the work of the IT and Volunteering Teams, we now have some great new templates to help you get started and build a website for your Branch or Group. Building your own site is the best option to aim for as you can include more information and really develop the site to suit the locality.

The Branch and Group website guidelines have also been re-vamped to help webmasters with different levels of experience access information more easily. New sections include:

- If you've built a website before (for experienced webmasters)
- If you've not built a site before (a step-by-step guide for getting started)
- Guidelines for the group or committee (with tips on how to find a webmaster and the benefits of having a site)

Current webmasters and accredited sites

If you haven't updated your site for a while, why not take a look at the new templates and see if they can be used to give your site a different look?

Both the updated Guidelines and new templates are available from Sarah Mayes on 01604 611825 or via email at sarah.mayes@mndassociation.org

A huge thank you to everyone who helped in getting the updated Guidelines and new templates ready.

Ruth Clark, Wendy Crofts and Sarah Mayes



Regional Care Forums

Here, in a special feature, we give two different perspectives on the value of Association Visitors attending Regional Care Forums (multi-disciplinary team).

An Association Visitor's perspective:

As a new Association Visitor it was quite daunting to be asked to attend a Regional Care Forum, all your uncertainties to be a visitor and inadequacies come to the fore of your mind, but you push all the negative thoughts away and get on with the task.

The meetings are held once a month, at the local Hospice, and all the care professionals meet in their lunch hour. A wide range of professionals attend, Physios, Dieticians, OT, Speech & Language, District Nurses, Ellenor Foundation, Day Therapist Hospice and on occasions Doctors, Matrons and other members of the medical profession.

On arriving I was put at my ease, realising we were all at the meeting for the same purpose, to try and make a

difference to the life of someone living with MND.

It took me at least a couple of months to get used to the medical jargon. All aspects of the disease are covered, from the All-Parliamentary Group on MND to RIG and PEG protocols and Stem Cell Research. Any issues arising are discussed and fed back from any working parties.

Then we review all cases of people living with MND in our area, confidentiality is kept by only referring to the person by initials. We review the last meeting's minutes and ask if any professional or myself has visited since the last meeting. Relevant information about visits is passed on to the group to be thrown open for discussion, and see how the person's situation can be improved and acted upon.

For example, I had visited a person living with MND and had been very concerned about a leg ulcer, foot pressure ulcer and sore toes. The dietician in the group said a lot can be done with diet to help, and would the person be open to a visit from her, I said I would ask. This case ended with a referral being made to the dietician.

In another case the person was still very active and independent but had had a couple of falls within the home and he was in the house alone for a number of hours. During the group discussion it was decided a Lifeline within the home would be a solution for the falls. I have arranged for the installation of the equipment and for payment by the local Branch.

Another concern to a person living with MND was she had been prescribed Riluzole and hadn't been able to get it from a number of pharmacies. My enquiry with National Office revealed a number been set up for urgent

supplies. I will pass this on to the group.

This type of group is essential to the smooth running of care for people living with MND, it needs a dedicated group that wants to improve the care and lives of people living with MND.

Maureen
Association Visitor, NW Kent

A professional perspective:

We have had visitor involvement for as long as the local forum meetings have been in existence (approx 1996).

We are an informal team - a group of professionals with an interest in MND working in different settings and meeting once a month at the local hospice.

We have regular attendance from: OT Social Services, Hospice Day Care, Ellenor (our local hospice at home team), community PT, dietician, speech and language therapist. DN teams and cares management and others join us when they have a pwMND on their caseload.

As far as I am aware there has never been any suggestion it is inappropriate for the visitors to attend. We make it clear to everyone who attends that what is discussed at the meetings is confidential and I have assumed that confidentiality is part of MND Association AV training.

I think the visitors have a very valuable role to play:

- They can often be our only point of contact with someone if they are reluctant to accept professional help
- They can be a real advocate for the person with MND in terms of pushing for the need for a piece

of equipment for example when we may have got bogged down in resource issues

- Even when there are lots of professionals involved they can give a different perspective
- They can flag up resources available from the MND Association when there are local difficulties
- They also facilitate funding via the local Branches for professionals to attend study days when necessary

I am sure there are also many other advantages and bonuses.

Catherine Knights
MS Specialist Practitioner
Current Chair, Dartford Gravesham and Swanley MND Forum

Why attend the National Conference – conferences are boring?

Is that what came to your mind when the National Conference flier came dropping through your door? Or perhaps you thought, what's the point, what will I get out of it, I already spend lots of weekends doing things for the Association, I've got no-one to go with?

Hannah Sookias from Staffordshire Support Group shares a very different experience: "The exciting buzz of people talking struck me as I entered the conference just after lunch on the Saturday. Everyone sounded happy that the two-day AGM & conference event was back!

"It had been a struggle getting there – my husband was working abroad that weekend so friends were looking after my two boys. As well as being a little nervous about going on my own, I surprised myself by feeling quite emotional as the last conference I'd

attended had been with my mum when she had MND in 2001.

“However, within minutes of arriving, I was happy to be there and knew the organisation hassles had been worth it. Being on my own meant I could take my time looking at the displays and I could talk to lots of different people without feeling I was ignoring anyone.

“Without seeking them out, I managed to meet Simon from East Surrey whose Free Spirit balloon launch idea we used; Sue, a trustee who was speaking at her mum’s Mother’s Union Branch in Stoke-on-Trent; and people from three of our neighbouring five Branches!

“I was fascinated by the talks concerning research and enjoyed taking part in the website & DNA Bank focus groups. The Branch and Group display really brought home to me how much is going on around the country and illustrated the different ways there are to raise funds and awareness.

“The conference helped me realise that progress is being made into identifying the causes of MND and that a cure will someday be found. The improvements in care (such as non-invasive ventilation) are encouraging and the way the Association is raising awareness is fantastic.

“My only regret is I was unable to attend the whole event – from the stories I heard the next morning, as well as missing the OSCARR presentations and a great speech from Lembit Opik, a good party was had by all! Is the booking form for 2007 available yet?”

Hannah Sookias
Publicity Officer, Staffordshire
Support Group
Email: staffs@mndassociation.org
www.mndstaffs.org.uk

Gossip from the Red Carpet!

Our sixth and most successful Oscarr event ever, this year we received a record number of nominations – 101 in all, which gave the judging panel a really difficult task in choosing winners.

The panel, made up of staff, volunteers and people with MND, were locked away with no chance of escape until the task was completed. After much deliberation they succeeded in selecting a winner and runners up for each category.

Hugh Cannon (Trustee), ably assisted by Heidi Macleod (Head of Care Services), who bore striking resemblances to Elvis and Dusty Springfield (or maybe Marge Simpson!), presented the awards at a glittering and entertaining ceremony at the Annual Conference that was well received by the audience.

We look forward to receiving your nominations in 2007 and presenting the awards to the recipients at the next Annual Conference Gala Night.

In the meantime - a big thanks to ALL our volunteers, every one a winner in their own right, for their hard work and dedication in the whole range of tasks undertaken on behalf of the Association and helping us all to Make a Difference.

Book your places now, see you next year!

See back page for winners’ details.



Regional Meetings 2006

Invitations to the Regional Meetings have been sent out. If you would like to attend but have received no correspondence, please contact me.

Central England and Wales Region

Sat 11 Nov Trident Business &
Technology Centre, Warwick

Southern England

Sat 4 Nov Best Western Gipsy Hill
Hotel, Monkerton, Exeter

Sat 11 Nov Directory of Social
Change, London

Sat 18 Nov Salomons Centre,
Tunbridge Wells

Sat 25 Nov Winchester Royal Hotel,
Winchester

Janet Bloor

**Regional Administrator – Central
England and Wales Region**

janet.bloor@mndassociation.org

DDI: 01604 611 827

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

Thursday, 12 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 any of these
courses and would like further
information, please contact one of us.

Anneka Minter/Tracey Lucas-Apea Recruitment and Training

Co-ordinators

Anneka.minter@mndassociation.org

Tracey.lucas-

apea@mndassociation.org

Direct Dial: 01604 611869

Publications List

The publications list has been re-
published and includes the dates of
when a leaflet or information sheet was
last updated.

To check you have the most current
version of information we produce,
please view the publications list on our
website www.mndassociation.org or
contact the Care Information Service.

Multikulti

Multikulti provides accessible,
accurately translated advice and
information in community languages.
Translations are available in 12
languages - Albanian, Arabic, Bengali,
Chinese, Farsi, French, Gujerati,
Portuguese, Somali, Spanish, Turkish
and Urdu; and they are currently
translating new material in three subject
areas - immigration, health,
discrimination & racism.

Certainly worth a visit if you haven't
already, www.multikulti.org.uk If you
do not have access to the Internet,
contact the Care Information Service.

Helpline 08457 626262 or
helpline@mndassociation.org

Sharon Schillerstrom

**Care Information Resources
Manager**

Sharon.schillerstrom@mndassociation.org

Direct Dial: 01604 611885

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.

Details: Elap Rotating Car Seat Unit. Double sliding complete seat in grey trim, with head restraint. For left hand passenger side in a 2002 Honda Civic. As new condition.
Asking price: Any offer to collect and take away (not fitted in car)
Area: Merseyside
Contact: Henry Lyth
Tel: 0151 648 2398

Details: Three-foot adjustable bed. SB400 Invacare. Low zone mattress, wooden side rails. Electrically operated. Purchased in July 2004 for £1,600. Exceptionally good condition.
Asking price: £800 o.n.o.
Area: South Warwickshire
Contact: Pat Peters
Tel: 01926 812818

Details: Scooter – Shoprider-cameo GK8. Maximum four miles/hr, eight mile range. Six months old, only used a few times. Price new £950.
Asking price: £300
Area: Enfield, North London
Contact: Mrs M Bird
Tel: 0208 3665432

Details: Apres full length body-dryer. Plug in free-standing (advised against a wall) 80 inches tall, three inches wide. Hardly used.
Asking price: £150
Area: Chelmsford, Essex
Contact: Mrs Salter
Tel: 01245 259273

Details: Rod linkage to convert automatic car to hand control. Fitted previously to a Vauxhall Zafira
Asking price: £100
Area: Scarborough, North Yorkshire
Contact: Bill O'Connell
Tel: 01723 373315

FUNDRAISING

Fundraising Re-organisation

As a result of the departure of Sue Thorn and Simi Epstein, as well as the introduction of the Research Foundation (see right), the Fundraising team has been re-organised.

The highlights are:

- Trusts and Major Donors are split
- Trusts joins Corporate Development under Mandy Lomax
- Major Donors becomes a separate entity under newly-recruited Veronica Martin
- Community Fundraising has a new head, Denise Davies
- Corporate Fundraising has two new fundraisers and a replacement Administrative officer
- Corporate, Trusts and Major Donors will share the services of a newly-created position of Prospect Researcher

The year ahead promises to be a very exciting and busy one for us here at the MND Association – we have an exciting new opportunity to raise funds for research through the MND Research Foundation, continue to expand and improve our corporate partnerships and to expand our range of sales items. Our aim with our new team structure is to ensure we are best positioned to take every opportunity we have to raise funds for the Association and people living with MND.

We look forward to working with you in the months and years to come to maximise our income and therefore our impact on people living with MND.

The Research Foundation

Research into MND has received a massive boost with the setting up of the MND Association Research Foundation.

The Research Foundation will lead to a huge increase in funding for MND research by the Association. The aim is to raise an extra £10 million over the next five years, and the Association is targeting major individual donors and companies to raise this money.

The Research Foundation will become the research-funding arm of the Association, and the first set of bids for funding by scientists will be considered by our Research Advisory Panel early next year.

As well as funding project grants and PhD studentships, money from the Research Foundation will also go to supporting Clinical Fellowships. This involves funding individual scientist-clinicians, whose role is to ensure that potential new treatments move from the lab to the clinic as quickly as possible.

The Foundation was due to be launched in Central London on 30 October.

Malcolm Tyndall

Director of Fundraising

Malcolm.tyndall@mndassociation.org



COMMUNITY FUNDRAISING

‘Message in a Bauble’...

It’s now nearly November and less than eight weeks to the festive season. Well organised people will already have their Christmas cards written out and soon

the postman will be dropping them through our doors.

So please make sure you have 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.

Elaine Wyspianski, Sally Harding and Anita Frith

Community Fundraising Team
fundraising@mndassociation.org

Direct dial: 01604 611860



Time to D'Feat MND

I am pleased to report this is proving to be a very popular event with many great ideas already being used and I am certain with more time to put this into your planning many more of you will enjoy taking part next year.

However, it would be brilliant if we could make this year an excellent start for this fabulous new National event. As such I would like to extend a personal request to you all to consider whether there is any chance you could organise some small event over the next month or so. If we all pull together I feel we can build a momentum and create a great success story.

I am having great fun putting together the National Office Mad Hatter's Tea Party and we have games, quizzes, and competitions, stalls, a raffle and maybe even a surprise or two to delight the staff and volunteers. Many local supermarkets and businesses are supporting the event and I will keep you updated with pictures and stories from the day.

A big thank you to all those who are already taking part in this brand new National event and we wish you every

success with your party or coffee morning.

For details of the events happening around the country please have a look at the Where's the Party page on the MND website and for those who would like their party included just let us know the about your event and it will be done.

Supermarket collections

In my previous roles I have arranged and taken part in many supermarket collections and gained a wealth of knowledge in how to organise and make the best out of them in terms of raising as much money as possible.

In particular I have a great deal of information on the best method to tackle Tesco for a collection as I was part of organising three National collections with them.

If any of you feel this is something you would be interested in, and you require some help and advice, then just give me a call and I would be happy to provide you with any help I can.

These can be lucrative for the amount of time and work required and the best time to do them is in the Christmas period as people are very generous - but be prepared for some novel ideas on how to achieve good results!

Sally-Ann Harding

Senior Community Fundraiser

sally.harding@mndassociation.org

Direct dial: 01487 815565



Great North Run 2006

The Great North Run was once again a huge success and special thanks must go to the Tyne & Wear Branch for organising all of the volunteers and for being so supportive.

Once again, Alan Riddle and his team did a terrific job taking people's photographs and emailing the images to them. I think that this makes such a difference to our runners and certainly makes them feel like they are special. To date, we have received a number of very positive and very touching emails from people, thanking us all for our efforts.

I just wanted to let you know that we are now in a position to be able to offer people guaranteed places for 2007. So if you have anyone that would like to run for us, just let me know.

Thank you once again to everyone involved in making this year's event another success! Watch this space for results of just how much we have raised!

Anita Frith

Community Fundraiser

anita.frith@mndassociation.org

Direct dial: 01604 611867



Swim Trek

As this is going to print, the magnificent Swim Trek team will probably have just completed their challenge.

Watch this space for more details on how they got on with hopefully some interesting photos!

Elaine Wyspianski

Community Fundraiser

elaine.wyspianski@mndassociation.org

Direct dial: 01604 611866



CORPORATE DEVELOPMENT

Any old phones? Any old phones?

We know how passionate all Association Branches are on the subject of raising funds so we wanted you to be among the first to hear about a new corporate fundraising initiative

which has the potential to raise significant funds for your Branch.

Every year millions of mobile phones are replaced and old models discarded. At best they lie forgotten in drawers and at worst they end up in landfill sites where they can release harmful substances into the earth.

The good news is that by encouraging friends, family and colleagues to turn out their cupboards and drawers and donate their old mobiles, you can generate an income of £3 per phone for your Branch - and protect the environment.

Full details are on their way but please start collecting today!

If you have any queries please contact me (see below).

Thumbprint Ball 2006

We would love it if you could join us at this year's Thumbprint Ball on Monday 27 November at The Brewery, Chiswell Street, London, EC1Y to celebrate the future and the promises it holds!

We are now able to offer a limited number of tickets at cost price to those of you who are involved in the running of our Branches. These tickets are available at £79 (plus VAT), so snap them up quickly before they all go!

There will be a live band, top disco, entertainers, casino tables and a chocolate fountain. Combine all this with an excellent meal and complementary bar and we are set to have a great evening and raise valuable funds for the Association.

To reserve your ticket or find out more please contact me (details below).

Please note cost price tickets are only available to MND Association Branch

volunteers (plus one guest). Tables are available at £1,200 (plus VAT) for 10 places or £1,350 (plus VAT) for 12 places. We also have a number of packages available.

Madeleine Collins
Corporate Development Support Officer

madeleine.collins@mndassociation.org

Direct dial: 01604 611832



TRUSTS

Possible grants for local Branches

The Trusthouse Charitable Foundation makes over 300 grants a year of which the majority are small grants of around £3,000. In the past the MND Association has been most fortunate to receive grants from this trust.

A revision to their application criteria now means that for the time being it is not appropriate to apply from National Office although applications from local Branches for local projects will still be considered.

Of particular relevance is their interest in hospice and palliative care, through which they aim to support the start-up or piloting of new initiatives in the provision of domiciliary care, training and education of palliative care specialists, volunteers and carers (excluding costs which are normally funded from statutory services).

Please visit their website www.trusthousefoundation.org.uk for more details. If your Branch would like to pursue this and make an application please contact me in order to avoid any duplication.

Leanne Dines
Trusts Administrator

leanne.dines@mndassociation.org

Direct dial: 01604 611861

SUPPORTER DEVELOPMENT

monday Lottery

The Association scooped almost £10,000 from our second **monday** lottery draw, held on Monday 7 August.

This made a total winnings of around £24,000 for people living with MND, plus we were also due to benefit from the draw on October 23.

The lottery works by choosing five different charities each week. The money raised through that week's draw goes straight to those charities to spend as they wish. The beauty of the **monday** lottery is that it's a win-win situation. For every pound spent, 30p goes directly to charity. And by playing your part, you have the chance to win up to £200,000.

To play, have a chance of winning cash prizes and support the Association at the same time logon to www.playmonday.com

John Blake
Head of Supporter Development

john.blake@mndassociation.org

Direct Dial: 01604 611835

My Symposium – help us spread the word

In the last few years we have posted daily updates from the Symposium on the website.

As we mentioned in the August issue of *The News*, we have more ambitious plans for this year including daily news stories - 'Daily Bulletins' and online diaries or Blogs.

The intended audience is people living with MND, Health and Social Care Professionals, clinicians and researchers not able to attend the meeting and even delegates at the meeting who wish to catch up with sessions that they missed!

We have created a special section of our website for the Symposium reports, called My Symposium. The website address is www.mndassociation.org/mysymposium.

To help promote these reports, we have produced a flyer. Stocks of these are available in National Office, so please help us promote the event in the UK by requesting copies and passing them on.

Please call either Belinda or Kate in the Research team or email us at research@mndassociation.org to request flyers.

Belinda Cupid
Research Manager
Belinda.cupid@mndassociation.org
Direct line: 01604 611847

Encouraging results from safety trial of potential new drug

US biotechnology company CytRx has recently completed a Phase II clinical trial of the drug Arimoclomol. The trial demonstrated that Arimoclomol is safe and well tolerated in people with MND.

Other preliminary data from the study suggest that Arimoclomol is capable of crossing the blood-brain barrier to reach the central nervous system. On the basis of these results, the drug will now progress to a trial of its efficacy in treating MND.

Arimoclomol enhances a natural cellular defence mechanism called the heat shock response, which helps cells cope with stress. This response can help prevent protein aggregation (clumping), which is known to be a feature of MND, and can also help prevent cell death.

A PhD studentship funded by the MND Association is now underway to study the protective mechanisms of the heat shock response in more depth.

Kate Arkell
Research Information Co-ordinator
Kate.arkell@mndassociation.org
Direct line: 01604 611806



BRANCH/NATIONAL FUNDRAISING EVENTS DIARY

DATE	BRANCH / EVENT	CONTACT NAME / TEL NO	
3 November	MND Association Charity Race Day, Fontwell Park Racecourse	Julia Franklin	01243 786109
4 November	Quiz, Bracknell	C Parsons	01256 359790
10 November	Quiz Night, Hamworthy Club Ltd, Magna Road, Bear Wood, Ploughman's Supper. Tickets £7. Send cheque and SAE to Branch Office at Poole Advice Centre	Audrey Beall	01202 668923
11 November	Coffee Morning at Kingsley Park Methodist Church, 10am-noon.	Kate Inchley	01933 664609
13 November	Open Meeting at Bridgemere Garden Centre	Joan Park	01270 624980
18 November	Trad Jazz Evening (Dennis Armstrong's Jazzband) Village Hall, Cranleigh, Nr Guildford, Surrey 8pm-11.30pm (Dancing)	Sallie Bushen	01483 274337
18 November	Fayre, New Milton Community Centre 10am-noon	Audrey Beall	01202 668923
18 November	Traditional Jazz Evening with the Oxford Classic Jazz Band at the Memorial Hall, Charlbury, Oxon. Bring your own picnic, Bar available. Booking advisable.	John & Stella Waterer	01608 677209
24 November	Abseil from The Citadel, Plymouth Hoe (by kind permission of the Royal Marines). Workers from the Royal Mail Centre are taking part. 2.00pm	Dawn Burley	01752 267407
26 November	Opera Live, Clare Hall, Haywards Heath. Popular arias and songs performed by Andrew Rees from the ENO and Jo Appleby of Amici Forever. 7.30pm	Carol Rieley	01444 482387

2-9 Decermber	Christmas Tree Festival, Dartford Methodist Church, Spital Street, Dartford	Eileen Finlay	01322 228169
3 December	Christmas Party, 2.30-4.30pm, Reaseheath Hall, Reaseheath College, Nantwich	Joan Park	01270 624980
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

SERVICES CONTACT SHEET November 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.

Subject	Service Contact
BENEFITS	Care Information Service 870
BRANCH ADVICE (General)	Sarah Mayes 825
BRANCH ADVICE (Regional)	
Northern Regional Manager	Steve Bell 08453 751820
Northern Regional Office	Lorraine Webster 01274 620309
VDC - North East	Chris Oakenfull 08453 751845
VDC - North West	Karen Hickmore 08453 751833
Central Regional Manager	Michelle Hodson-Curran* 08453 751830
VDC - West Midlands & Wales	Angela Lea 08453 751834
VDC Central / East Midlands & Anglia	Ruth Clark 08453 751829
Southern Regional Manager	Mike McKevitt 08453 751840
VDC -South Central / S West	Su Starkey 08453 751839
VDC -South East	Stefanie Cormack 08453 751848
BRANCH FUNDRAISING SUPPLIES	Ros Norris 826
BRANCH MAILINGS (inc <i>The News</i>)	Sarah Mayes 825
BREATHING SPACE KITS	Care Information Service 870
CAMPAIGNING	Alison Railton 842 / Mark Hill 844 / Julie Compton 0115 9858346 (Central Region only)
CARE DEVELOPMENT (General)	Julie Lavender 874 / Heidi Macleod 871
CARE ISSUES & ADVICE:	
National Office	Care Information Service 870
Regional	RCAs - see over for listing
CARE CENTRE PROGRAMME	Debra Garside (programme head) 08453751843
CHRISTMAS AND SPRING CATALOGUES	Sarah Mayes 825
CLINICAL TRIALS	Belinda Cupid 847 / Marion Reichle 849 / Brian Dickie 848
CONFERENCES	Pam Aston 845 / Kim De Lancey 822
DESPATCH	Kay Attard 818 / Mick Paine 811
DIARY OF EVENTS	Ros Norris 826
EQUIPMENT FOR DISABILITY	Care Information Service 870
EQUIPMENT LOAN	Equipment Loan Service 802
FINANCIAL SUPPORT	Jane Skelton 876 / Heidi Macleod 871
FINANCE & BRANCH ACCOUNTS	Colin Byer 808 / Teresa Morrisroe 856
FUNDRAISING	860
Affinity Credit Card	John Blake 835
Appeals	Tracey Walton 862 / John Blake 835 / Angeles Garcia 862
Branch Fundraising	Denise Davies 833 /Elaine Wyspianski 866 / Anita Frith 867
Community Fundraising	Denise Davies 833 /Elaine Wyspianski 866 / Anita Frith 867
Corporate Development	Mandy Lomax 864 / Madie Collins 832 / Derek Thorpe 01242 573980
In Memoriam Donations	Esther Fifield 881 /Shabz Khokhar 830
Legacies	Liz Robson 863 / Stephen May 865
Lottery	Malcolm Tyndall 836
Marathon	Elaine Wyspianski 866 / Anita Frith 867
Raffles	Elaine Wyspianski 866 / 833
Tax Effective Giving / Gift Aid	John Brownsell 883
Trusts	Nicola Wilkinson / Kristina Robson /Janet Lee (Voicemail) 828
GRANTS: Research	Marion Reichle 849 / Belinda Cupid 847 / Brian Dickie 848 /Kate Arkell 806
HELPLINE	Care Information Service 870

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

CARE ISSUES & ADVICE (Regional Care Advisers) RCAs

Telephone

Northern Region

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

Central Region

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

Southern Region

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

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. eg.

christine.morton@mndassociation.org * Email address is michelle.hodson@mndassociation.org

** Email address is carol.thomaswyllie@mndassociation.org

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