

## Cheshire Branch

June 2011 Issue No 1102/14



### Spring Conference

By Hal Bailey

This year's Spring Conference was held on 9<sup>th</sup> April 2011 at the Radisson Blu, near Manchester Airport and was well attended, amongst the audience was Joel, Marion, Margaret, Hazel and myself representing the Cheshire Branch committee.

The meeting was chaired by Alun Owen who is currently the Secretary of the Merseyside Branch and was voted on as a Trustee of the National Association in September 2009.

The first speakers were Fiona Taylor - Head of Care Standards Development and Raj Johal - National Campaigns Manager and they presented a paper on "How will changes to the NHS and social services affect people with MND?"



Delegates at the Manchester Spring Conference



This was based on recent announcements by the Coalition Government on major reforms to the NHS, social services and other areas supporting people with MND. This session provided a brief overview of what is currently happening, what will change in the future, and how people with MND, carers and supporters of the Association can get involved with work to influence these important changes.

A presentation was given by Steve Bell - Director of Regional Care North on "Ensuring the best possible standards of care and support" The presentation focused on the work of the National and Regional Care directorates over the last year and looked forward to provision in the future.

The challenge to our provision was discussed in light of changes in the external environment, and in particular, changes within both health and social care. The impact of our current care service provision to people living with MND, their families, carers and to health and social care professionals was described.

The final paper, "Measuring MND: the search for biomarkers" was presented by Janine Kirby PhD who is a senior lecturer at the new Sheffield Institute for Transitional Neuroscience. The talk focused on how we are using blood, skin cells and brain and spinal cord tissue to identify markers of MND. These have the potential to aid in diagnosis, track the course of the disease and provide further understanding of why motor neurones die in people living with MND.

During the course of the event there was ample time to ask questions, to circulate, and to see the various exhibitors who were displaying their aids.

#### Diary Dates

June 18 <sup>th</sup>	Walk 2d' Feet - Nantwich Town Centre
June 25 <sup>th</sup>	Collection Day - Crewe Town Centre
June 25/26	Arley Garden Festival

For further details go to [www.mndcheshire.org](http://www.mndcheshire.org)



## Food for thought

*An attractive blonde arrived at the casino.*

*She seemed a little intoxicated and bet twenty-thousand Euros on a roll of the dice.*

*She said, 'I hope you don't mind, but I feel much luckier when I'm completely nude'.*

*With that, she stripped from the neck down, rolled the dice and yelled,*

*'Come on, baby, Mama needs new clothes!' As the dice came to a stop, she jumped up and down and squealed...*

*'YES! YES! I WON, I WON!'*

*She hugged each of the dealers and then picked up her winnings and her clothes and quickly departed.*

*The dealers stared at each other. Finally, one of them asked, 'What did she roll?'*

*The other answered, 'I don't know - I thought you were watching.'*

**MORAL OF THE STORY**

*Not all blondes are dumb, but all*

**MEN...ARE MEN.**

## Coffee Morning



Following on from the news flash in the March edition of the newsletter Marion, Margaret and I went to the coffee morning organised by the Women's Guild at the Parkgate and Neston United Reform Church.

Prior to the event there was a meeting of the Women's Guild which was held on the Wednesday at which Amy, a committee member and an Association Visitor presented the facts about MND. There was nothing but praise for the talk from those who attended.

It was fortunate that the sun was shining as there was such a large number who dropped in for coffee and a hot cross bun that some people sat outside the Church Hall.

On behalf of the Cheshire Branch I would like to thank everyone who attended for their generosity, and in particular Margaret and Howard Starr. The total raised was £1,025.00 which will enable us to continue to support people living with MND in the Cheshire area.

*Sadly a short while after the event Howard suffered a heart attack and has since lost his battle with MND and passed away peacefully on 18<sup>th</sup> May.*

## Wilmslow Half Marathon

By Zoe Lawson



Thanks for taking the time to visit my JustGiving page in memory of Rob Shaw. As many of you know, Rob fought Motor Neurone Disease (MND) with enormous bravery, determination and dignity.

I made a promise to Rob last year that I would take part in the Wilmslow Half Marathon 2011 which was held on Sunday 27th March and all money raised will go to MND.

My target was £350. Altogether, including gift aid; I managed to raise £707 through your generosity.

## 3 Peaks Challenge

Joel Hewit is to take on the "3 Peaks challenge" in 24 hours on 11<sup>th</sup> June 2011.

He is hoping to raise £2,500 for the MND Association. He is undertaking the "3 Peaks Challenge" with 8 of his close friends.

Joel says "This charity means a lot to me and my family and I would like to express my gratitude to all those who have helped my grandfather Tom Bourne."

He has set up [www.justgiving.com/hewy](http://www.justgiving.com/hewy) for donations, the total contributed at the time of writing stands at £395.00. So please dig deep and donate now.



Joel Hewit pictured with his grandfather Tom Bourne

## Newsletter

### This is your newsletter

So please let us have your contributions. These can take the form of 'humour', 'personal experiences', 'hints and tips', 'questions', 'holidays' 'photographs', and any other information that you might think of interest to our members.



Austen



Shakespeare

You do not have to be a Jane or a William to submit any of the above.

So please do submit your contributions

And make this newsletter work for everyone in Cheshire



## Scambuster booklet

(Extracted from the MND Associations publications)



A USEFUL booklet has been produced by the Office of Fair Trading, called *Scambuster: Your guide to beating the scammers*.

The booklet has been designed to inform the public of the danger of scamming through unsolicited letters, emails and phone calls, or through websites.

Case studies of specific scams are provided. If you suspect you have been subject to a scam, contact Consumer Direct on 08454 04 05 06.

Free copies of the *Scambuster* booklet can be ordered by calling 0800 389 3158 and different formats are available

## One-stop for policy & campaigning

(Extracted from the MND Associations publications)



WE now have a brand new dedicated campaigning website

This is the place to go to find information on all our campaigning activities, sign up to the new MND Campaign Network, participate in quick and easy campaign actions, and browse our archive of policy positions and consultation responses affecting people with MND. what you will find when you visit the website:



**The Campaign Network** - For the first time, you can sign up online to our new Campaign Network. It is free to join, and you can do as little or as much campaigning as you like. We want to build a strong network of individuals who will take action, spread the word and support our campaigns.

**Take Action** - This section will allow you to take simple direct campaigning actions online, for example, emailing politicians. These actions only take a few minutes but make a huge difference to our campaigns.

**Policy** - This section will provide all our views on policies affecting people with MND. You will also find all our responses to recent Government consultations.

**National and Regions** - These pages will allow you to see what campaigns and events are happening in your area.

**Events** - Visit this section to see where we are holding campaigning events, workshops and sessions on campaigning and policy affecting people with MND.

**Blog** - Some of you may have been keeping up-to-date with our MND Campaigns wordpress blog. We have moved this over to our new website, so it really is your one-stop-shop for all information on our campaigning and policy work.

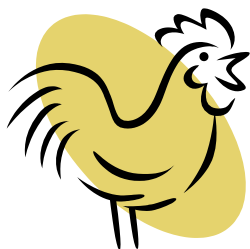
Please check out the website [www.mndcampaigns.org](http://www.mndcampaigns.org) today and tell your friends, family members and colleagues about it too.

## Humour!

(Courtesy of Trevor)

*A lady was attempting a jigsaw but could not get started, so she phoned a neighbour for help.*

*After awhile he came round and asked what was the problem*



*"well the picture on the front of the box is a cockerel, but I can't figure it out"*

*He replied "put the cornflakes back in the box dear"*



## Online forum

(Extracted from the MND Associations publications)

OUR online forum is going from strength to strength, providing a safe place for those affected by MND to share experiences and support each other with the challenges of living with the disease. Please continue to make those affected by MND in your area aware of the forum at <http://forum.mndassociation.org>

## Support Meetings

By The 2 M's



If you are living with MND or are a Carer of someone Living with MND or are someone who knows someone living with MND and have not had any contact with the Branch, our branch contact is Marion (07929 732958) and if you have a question that she cannot answer she will know someone who can. If e-mailing is easier why not contact her on [marion.38@btinternet.com](mailto:marion.38@btinternet.com)

Would you like to meet us at one of our informal get togethers for tea and cake in and around Cheshire – two of our venues are Hotels and one is a Garden Centre.

These are very friendly and positive meetings with an exchange of ideas and hints and tips. We would love to meet you, and if you think this is for you please contact Marion on the above number or Margaret on 01565 634831.

## NarrowBoat Trip

By The 2 M's

On a fresh, sunny Wednesday morning at 10.00 am 22 members of the Branch met at the Cheshire Cat at Christleton to travel on 2 narrowboats named "The Pot of Gold", and "Michael Hayes" to travel through 5 locks to Cow Lane Bridge in the centre of Chester, and back again.

The narrowboats are owned and operated by Wirral Community Narrowboat Trust. Each boat has a wheelchair ramp and lift, a flush toilet, central heating, full cooking facilities incl. refrigerator, kitchen utensils, tea towels, plates, cutlery and crockery.

We set off at approximately 10.45am and tea and biscuits were served. As the narrowboats leisurely made their way to Chester, the weather improved. We reached Cow Lane Bridge at about 1.00pm and everyone disembarked and went to the "Frog and Nightingale" (see pictures). On the way back a picnic lunch was served.



A day out on the Shropshire Union Canal



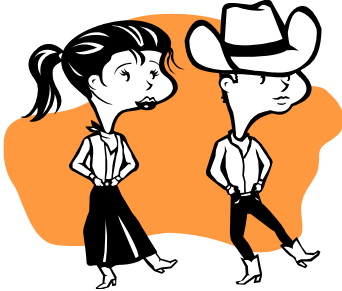
We arrived back at the Cheshire Cat about 4.15pm after a very relaxing day on the canal.

It would be remiss if we didn't mention, and thank, the volunteers who operate and crew the narrowboats. They went out of their way to ensure that we had a very enjoyable day.

The canal trip will be certainly featured again, as everyone thoroughly enjoyed the day.

## APA Line Dancing

Once again Danny & Margaret Boyd presented cash this time totalling £150.00. This money was raised by Ann and Alan from APA Line Dancing. Margaret had been an active member of the club for many years.



This is becoming a regular feature as every quarter they are donating money to the Branch.

## Strawberry Evening



Don't forget to buy your tickets for the Strawberry Evening.

Tickets are £7.00 to include refreshments and entertainment and are available from Hazel who can be contacted on 01270 626222.

This year the evening is being held on 16<sup>th</sup> June at Nantwich Football Club.



## Cheshire Building Society

Extracts from the D2d Cycle Challenge Blog

A great crowd turned out, at Pride Park in Derby, to wish the riders well, including representatives from the MND Association, Chris Woodhead Foundation (CWF) and Rammie from Derby County Football Club.

The riders arrived at the Macclesfield Branch to a great reception from employees, the media, and customers. In amongst the crowd were Joel, Marion, and Margaret and Hal representing the Cheshire Branch of the MND Association.

On day 2 and only 5 miles out of Macclesfield, the riders had been stopped twice by members of the public who wanted to make a donation.



The riders began the busy ride through Oldham, Rochdale and Burnley, before heading out into the countryside and the beautiful scenery of the Yorkshire Dales. 52 miles later the riders arrived at the Craven Arms in Giggleswick.

The riders arrived at the Cheshire Building Society in Macclesfield

Day 3 began with a huge uphill slog to Penrith, and at the top of Shap summit in the Yorkshire dales the riders had lunch before the final push into Penrith.

It was a late start on day 4 as a couple of bikes needed some attention, and one of the riders had to set off on a borrowed bike until a new part was fitted at the most helpful bike shop in the world – Arragon' of Penrith. After some great uphill and down dale section the riders made it over the border into Scotland. Lunch was taken at Gretna Green and then onto Moffat, passing thru Lockerbie.

After 5 days and 280 miles the riders leave Livingstone and begin the final leg to Dunfermline. The riders make it to South Queensferry for a quick photo call, but only half the bridge is visible as a thick fog descends over the North Bank. Eventually after 300 miles and 6 days later the riders made it over the finishing line in Dunfermline being greeted by a tremendous crowd including representatives of MND Scotland, MND Assoc. and the CWF

Target: **£100,000.00**

Raised so far: **£91,197.00**

<http://www.justgiving.com/d2d-Challenge>

### Footnote:

The latest news from the Cheshire Building Society branches participating in our area which are: Accrington, Chorley, Crewe, Culcheth, Leigh, Lymm, Middlewich, Nantwich, Northwich, Stockton Heath, Warrington, Wigan, and Winsford, is that they have SMASHED through the £10k barrier!!!

The following branches have raised over their target of £1,000; Wigan £1,516.74, Leigh £1,450.00, Crewe £1,351.00, Winsford £1,200.15. Our thanks go to all the branches who have raised a total of £10,114.57 to date.

## Joining forces to challenge benefit

(Extracted from the MND Associations  
publications)



WE have  
joined forces  
with disability  
charities

across the UK to challenge the  
Government's welfare reform  
agenda and cuts to disability  
benefit support.

We believe the proposed  
changes will disadvantage  
many people with MND and  
their carers, and we need your  
support to make the  
Government listen and stop  
the cuts.

If you do not have access to the  
internet, or for more  
information on this campaign  
and how to get involved,  
please contact Raj Johal, on  
020 8551 2152.

For more information, please  
visit  
[www.mndcampaigns.org/take  
action](http://www.mndcampaigns.org/take-action)  
or  
[www.hardesthit.org.uk](http://www.hardesthit.org.uk)



13<sup>th</sup> – 19<sup>th</sup> June  
Supporting the UK's 6 million  
Carers  
Visit their website  
[www.carersweek.org](http://www.carersweek.org)

## 800 to take part in clinical trial

(Extracted from the MND Associations publications)



**A LARGE clinical trial to test the safety and effectiveness of a new drug called dextramipexole (formerly known as KNS760704) is expected to get underway within the next few months.**

Six centres in England will be recruiting participants with MND who experienced their first symptoms less than two years before the start of the trial. The 18-month trial, also known as the EMPOWER study, is being organised by a pharmaceutical company called Biogen Idec and will involve over 800 people with MND in total, recruited from ten countries across the globe.

The six trial centres in England will be located in Newcastle-upon-Tyne, Sheffield, Liverpool, Birmingham, Oxford and London. Although it is not expected to begin until mid-2011, awareness of the trial is already quite high among people affected by MND as it is being discussed on a number of internet forums.

Recruitment for the trial has not yet started and we do not yet have contact names at the six UK centres. We know that the trial will only be open to people who have had their symptoms for less than two years before starting on the trial but other than that we do not have details of the criteria that people will need to meet in order to take part. However, as soon as we have managed to get hold of all of these details we will produce an information sheet for people affected by MND. This will be available to order from MND Connect or to download from our website at [www.mndassociation.org/clinicaltrials](http://www.mndassociation.org/clinicaltrials).

The research development team at national office would be happy to answer any questions and can be contacted on 01604 611880 or at [research@mndassociation.org](mailto:research@mndassociation.org)

People who are interested in taking part in the trial should also discuss it with their neurologist, or get in touch directly with one of the trial centres, once contact details have been made available.

## Carers Lunch

By Joel Millett

Following the success of last year's Carers Lunch it was decided to make this an annual event, so as not to break a winning formula we again held the event at Nunsmere Hall, Oakmere, on 25<sup>th</sup> May. At the heart of Delamere forest the hotel is surrounded by a 60 acre lake which is quite appropriate as the hotel was once the home of Sir Aubrey Brocklebank, chairman of the famous Cunard shipping line.

In attendance along with the 8 carers was Kathy James (Regional Care Development Advisor for MND Assoc. and Ros Graba (Senior Occupational Therapist for Cheshire East).



During the relaxed 3 course lunch the ladies were both on hand to answer questions from the carers. After lunch the conversations continued over tea and coffee. Everyone agreed that the event had been a great success.

## Newsletter

If you would like to receive your newsletter by email then please contact Hal Bailey on

[hal@mndcheshire.org](mailto:hal@mndcheshire.org)

## Committee Staff



Marion Chadwick (centre) being presented with a long service award by Alun Owen a Trustee of the Association and Margaret Bailey



Nancy Dutton being presented with a bouquet of flowers by Margaret Bailey to celebrate a memorable birthday and her efforts in raising money for the Branch over many years.

## Financial Stuff

Summarised Accounts as at 30 <sup>th</sup> April 2011			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	1,779.81	Financial Support	2,378.13
In Memoriam Donations	0.0	National Office	13,854.10
Fund Raising	587.00	Branch Admin costs	834.91
Gift Aid	0.0	Publicity	330.72
Sundries	720.00		
		<b>Total Expenditure</b>	<b>17,397.86</b>
		<b>Surplus/Deficit</b>	<b>14,311.05</b>
<b>Total Income</b>	<b>3,086.81</b>	<b>Total</b>	<b>3,086.81</b>

## AGM

Joel Millet, Acting Chair, opened the meeting thanking everyone for attending. Then the presentations were made. He proceeded to identify the successes of the previous year's activity. He then went on to outline some of the events of the year ahead, including the carer's lunch and the barge trip.

Martin White presented the accounts, which had been audited, where income has gone up by 60% over the previous year. The main increase came from fundraising – highlights include Roger Greigs cycle ride which raised over £4000, the strawberry evening which raised over £1000, and of course the biggest income came from the Arley Event where over £18,000 was raised. Martin thanked everyone involved for helping to raise our funds.



Our guest speaker David Hanson, Campaigns and Development Manager in the External Affairs Directorate, gave an overview of current reforms that will affect those people living with MND and what the association is doing to help. The presentation included topics such as the current planned changes to NHS, Welfare Reform Bill where there are 2 main changes: Universal Credit – a new type of benefit which replaces everything apart from DLA and attendance allowance, and the introduction of Personal Independence Benefit.

David then spoke about a new initiative called Cuts Watch and asked us to get involved by letting them know how the cuts are affecting you. The Association are collecting evidence so they can use it when lobbying MP's, in the media etc. He explained that case studies are vital for them when lobbying. You can do this on-line at

[http://www.mndcampaigns.org/take\\_action/68\\_cuts\\_watch](http://www.mndcampaigns.org/take_action/68_cuts_watch)

Hazel Francis thanked David for speaking and then refreshments were served.

[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) MND Connect offers support, information and advice to: People living with MND, Health and Social Care Professionals, staff and volunteers

Kathy James is the Association's **Regional Care Development Adviser** (RCA) working in the Branch area, who has detailed knowledge of the care and management of MND.

Kathy can be contacted on 0845 375 1832, or email: [kathy.james@mndassociation.org](mailto:kathy.james@mndassociation.org)

## Branch Contacts

Chair	Joel Millett	01625 525409	<a href="mailto:joel@mndcheshire.org">joel@mndcheshire.org</a>
Secretary	Clare Ward	01565 653475	<a href="mailto:clare@mndcheshire.org">clare@mndcheshire.org</a>
Treasurer	Martin White	01695 628292	<a href="mailto:martin@mndcheshire.org">martin@mndcheshire.org</a>
Branch Contact	Marion Chadwick	07929 732958	<a href="mailto:marion.38@btinternet.com">marion.38@btinternet.com</a>
Publicity Officer	Helen Parker	07834 773113	<a href="mailto:helenswords@sky.com">helenswords@sky.com</a>
Newsletter Editor	Hal Bailey	01565 634831	<a href="mailto:hal@mndcheshire.org">hal@mndcheshire.org</a>
Fund Raising	Hazel Francis	01270 626222	<a href="mailto:hazel@mndcheshire.org">hazel@mndcheshire.org</a>

## Association Visitors

Ann Barlow	01606 891027	<a href="mailto:ann@mndcheshire.org">ann@mndcheshire.org</a>
Joel Millett	01625 525409	<a href="mailto:joel@mndcheshire.org">joel@mndcheshire.org</a>
Amy Phillipson	07870 199435	<a href="mailto:amy@mndcheshire.org">amy@mndcheshire.org</a>

## Important Notice

*If you know anyone living with MND or a carer of someone living with MND and they have not had any contact with the Branch, please pass on your copy of the newsletter and encourage them to make contact with us. All our contact details are shown above.*

*Would you like to meet us at one of our informal get togethers for tea and cake in and around Cheshire – two of our venues are Hotels and one is a Garden Centre. These are very friendly and positive meetings with an exchange of ideas and hints and tips.*

*Again we would love to meet you, and if you think this is for you please contact us.*



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