

### Branch AGM held on Sunday 28<sup>th</sup> March

This year's Branch AGM was held at Nantwich Methodist Church, Hospital Street, Nantwich, on Sunday 28<sup>th</sup> March. Our speaker this year was Kate Gooding who is the Care Services Manager for the Association.

Over 30 members and friends of the Branch attended the meeting.

Chairs Report - Julie Williams presented her report for the year and highlighted the salient points. The support groups organised by the Branch, now at 3 venues across Cheshire, continue to provide a valuable opportunity to meet others, share experiences and information. In addition trips to The Arley Estate and Bridgemere Garden Centre were arranged during the summer.



Awareness is one aspect that we all try to improve and our thanks go to Frank and Doreen Casey who again organised a display in Northwich Library during Awareness Week.

In Cheshire, we now have 2 Association Visitors and Amy Phillipson who is a member of the Committee starts her training in April to become an AV.

The work of the Branch has again been recognised by National Office by awarding the Branch for the second year running an 'Oscarr' for Branch Achievement. This was emphasised at the meeting, by Karen Hickmore who is our regionally-based Volunteering Development Coordinator, who highlighted the work undertaken by the Branch.

In conclusion Julie highlighted some of the events taking place this summer, including the annual strawberry evening, Arley Flower Festival, and again a 'Walk to d'Feet' in Nantwich. Further information on these events and others can be found on the Branch's web site.



After the meeting an excellent presentation was given by Kate Gooding who is the Care Services Manager for the Association. The presentation included amongst other things information on the work of MND Connect Team, the Financial Support Team, Equipment Loan and last but not least the Association's partnership with AbilityNet. Kate also gave an indication of the vast sums of money that are required to provide the support, both financially and in provision of vital equipment that is needed for people living with MND.

The presentation was appreciated, enjoyed and applauded by all present at the meeting.

#### Diary Dates

June 11	Strawberry Evening, Community Centre Tarporley
June 19	Walk 2 D'Feet Community Centre Tarporley
June 26/27	Arley Garden Festival

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

## *Food for thought*

### My Next Life

In my next life I want to live backwards. You start out dead and get that out of the way.

Then you wake up in an old people's home feeling better every day.

You will get kicked out for being too healthy, go collect your pension, and then when you start work, you get a gold watch and a party on your first day.

You work for 40 years until you're young enough to enjoy retirement.

You party, drink alcohol, and are generally promiscuous, and then you are ready for high school.

You then go to primary school, you become a kid, and you play. You have no responsibilities; you become a baby until you are born.

And then you spend 9 months in a luxurious spa like conditions with central heating and room service on tap, larger quarters everyday and then Voila!

I rest my case.

## 30<sup>th</sup> Anniversary Royal reception at St James's Palace

To commemorate 30 years of the Motor Neurone Disease Association, the charity's royal patron, HRH The Princess Royal, held a reception at St James's Palace on 6 May attended by 300 guests.

As a Branch we were lucky enough to be chosen to send a representative as Hal and Margaret Bailey were invited by MND Association National Office to attend the event, for the work they have done in raising the awareness of MND. Of the 300 guests who were invited, 100 were chosen to be presented to Princess Anne, and Hal and Margaret had the honour to meet and speak to the Princess.

The event provided an opportunity for The Princess Royal to meet representatives from across the Association to mark this special occasion in the Association's history.

Many of those who founded the Association 30 years ago attended the reception. Back then they were driven by their own devastating experiences of the disease to support all those affected by MND and to help fund research to identify future treatments and one day a cure. This remains the charity's mission today.

The reception brought together a wide selection of supporters and volunteers from across the UK, all of whom have played a significant role in providing support to those living with MND and their families and carers.



With Princess Anne are Julie Draper, a MND Association Trustee and Margaret and Hal Bailey

"This event marks a huge milestone for the Association. Thanks to the support and dedication shown by our volunteers we have grown over the years to become a national charity which has made immense progress for people with MND. I am proud to say that the MND Association remains true to its original aims of support for people with MND and research for a cure. Our charity was started by volunteers and volunteers remain the lifeblood of the Association."

Kirstine Knox, chief executive of the MND Association, said:

Both HRH The Princess Royal and the President of the MND Association, Prof Colin Blakemore, spoke at the event to look back on the past 30 years and the advances made in that time and to reflect the MND Association's commitment to a world free of MND.



## 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.*



One of our members, Trevor Druce, has recently visited the Livability hotel in Llandudno and highly recommends it. Equipment can be hired and there are carers in attendance at the hotel.

Trevor is planning to go to Minehead to try another hotel in the chain.

Further information can be found on their website at

[www.holidaysforall.org/](http://www.holidaysforall.org/)

or phone  
08456 584478

## Appeal for Friends of the Branch

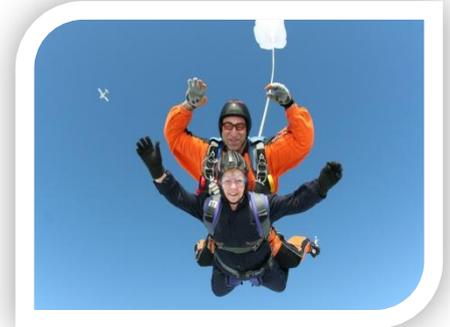
### Could you be our 'Friend'?

who might be willing to help us out from time to time, for example by helping at a collection day or other fundraising event. This would really suit you if you are keen to help and want to make a real difference but don't have the time for a regular commitment. If you would be willing to be contacted periodically to see if you could help us out on such occasions, please get in touch with any member of the committee and let us know how you would prefer to be contacted

## SKYDIVE

By Louise Woodman, Liz's daughter

Liz Hartland is afraid of heights!! Last time Liz went up in a small plane was many years ago, and she came down with her head between her knees and the smelling salts in her hand and vowed never again! But Liz did a skydive on 5<sup>th</sup> May 2010, with her son Paul, to raise money for the motor neurone association. Her son Paul is 33 and was diagnosed with MND in October last year.



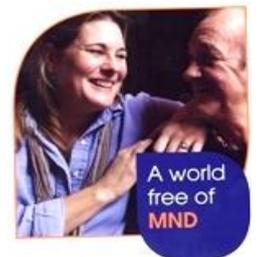
## Spring Conference 2010

By Hal Bailey

The conference was well attended, both by professionals and exhibitors and also members of Branches and the Cheshire Branch. The facilities at the venue were very good; the hotel had reserved disabled parking bays for those attendees requiring them.

There were very useful and information presentations from senior staff at the MND Association, from Steve Bell, Director of Regional Care for the North, on "What is happening in Care?", from Belinda Cupid, Research Manager, on "Funding world-leading research and the importance of clinical trials", and from John Kell, Policy Manager, on "Join our call for a National Strategy on MND". Each presentation was followed by a question and answer session.

A new feature session was called "Together we can make a difference" which I thought was a valuable addition to the Conference format as it was an interactive session not restrained to any speakers presentation, and it allowed delegates to spend some time with the exhibitors, and then to be able to table written questions to the panel.



To sum up, the day was very enjoyable, as well as being informative, it brings people together and you can exchange views with individuals you probably would not meet if it weren't for these types of events.



**A weekend away** – Read about Mick Jackson who has always been a biker at heart at his favourite motorcycle rally. That rally is the National Association of Bikers with a Disability's annual 'You've Been NABD' Rally at Chelford at [www.mndcheshire.org/4.html](http://www.mndcheshire.org/4.html)

## Fund Raising and Donations

The following monies were received by the Branch during the last three months. It is through such generous gifts that the Branch can help the people of Cheshire to be as independent as possible for as long as possible.

## APA Line Dancing

Once again Danny & Margaret Boyd presented cash this time totalling £305.

This money was raised by Ann and Alan from APA who had celebrated a very special birthday for Ann, and instead of presents had requested donations for the Branch.

Margaret had been an active member of the club for many years.

## Delamere Park Ladies' Club

Our thanks go to the above club for the donation of £200, which will be used for the benefit of the people living with MND in Cheshire.

## Prestbury Methodist Church

Prestbury Methodist Church recently held a coffee morning in aid of MND and very kindly donated the proceeds to the Cheshire Branch. The coffee morning was held in memory of Margaret Hardy's husband who died from MND a few years ago.

This donation of £520 will all be used for local people. It is through such donations that we can help the people of Cheshire to be as independent as possible for as long as possible.



## Rotary Club of Sandbach



Allen Williams, Julie Williams, Gill Merry, President Keith Merry, Margaret Hutchinson, Henry Blowey, David Heyes, Max Leese

Rotary Club of Sandbach celebrated their 64th Charter Celebration on Friday 26th March at The Masonic Hall, Sandbach.

Julie Williams the Branch Chair was invited by President Keith Merry to speak after dinner. This consisted of amusing speech and songs in the style of Victoria Wood. Julie was accompanied on the piano by Rotarian Bill George. The raffle donations which were collected and exceed £300 were donated to the Branch for the benefit of people living with MND in the Cheshire area.

## The Praise and Fellowship Group

at the Parkgate and Neston United and Reformed Church have donated £60 in honour of Rev Howard Starr who has recently been diagnosed with MND. Howard is a member of the church and has provided tremendous support over many years.

## Pennies from Heaven



Amy Phillipson, who is currently training to be the Branch's next Association visitor, works for the Wirral PCT and has successfully nominated, on behalf of the Branch, the MND Association to be the recipient of this financial years donations from the 'Pennies from Heaven' scheme.



'Pennies from Heaven' is an innovative coin collection scheme. It enables workers to donate spare pennies from their income to charity by rounding down net salaries of individuals who join the scheme, to the nearest pound with the spare pennies being donated to a nominated charity. The most anyone can give per payslip is £0.99. All donations are eligible for Gift Aid which means an additional 28% is added by the government.

Each Organisation must choose one benefiting charity which can be changed annually. For example, this might be a national charity or perhaps your local hospice. Each calendar quarter the total donations will be paid over.

## The MND Association 2010 raffle is now open!

We shortly have our first allocation of raffle tickets, and with your help, are looking forward to the 2010 raffle being a great fundraising success for us.

Please goto  
[www.mndcheshire.org](http://www.mndcheshire.org) for  
more information.

## Branch Leaflets

Volunteers are required to distribute leaflets to locations within the Cheshire area e.g. doctors surgeries, libraries, CAB offices etc.

Please contact Margaret on  
01565 634831



## Date for Carers

A lunch is being arranged for Carers at Nunsmere Hall on July 22<sup>nd</sup>.

Further details to follow from  
Julie Williams

## Concert for St George's Day

Hankelow Methodist Church held a concert on 22<sup>nd</sup> April where approximately 80 people had a very enjoyable time singing traditional songs such as "I'm Henry the Eighth I am" and "Land of Hope and Glory". Afterwards refreshments were provided.

Our thanks go to all those who attended for their kind donation of £200 which was collected as part of the admission fee.



**BOOTHS** Supermarket in Knutsford collection on Friday 30th April, raised a fabulous total of £482.22p. Our thanks go to the Manager, friends and members of the Branch who gave up their time and helped to raise the money on the day.

## LeJog Training

By Roger Greig

I think my life is turning full circle. When I was a kid in the school holidays, and had homework to do, I'd think "I've got loads of time that can wait a while". Then of course the holidays would almost be over before the reality of the situation dawned.

When I decided to do the ultimate long distance UK bike ride, scheduled for some nine months ahead, beginning this August. I figured I had plenty of time to prepare. The similarity is uncanny, and not in the least bit funny. My website, [www.dodgergammon.co.uk](http://www.dodgergammon.co.uk) has a countdown timer, displaying the number of days until the start of the ride, which as I write this in early May, reads just 110 days.

My plan is to cycle the 900 miles from Lands End to John O'Groats, over 11 consecutive days in August, to raise funds for MND Association. I will have a companion Rob, who is equally unfit and ill-prepared as myself.

I was always going to wait until the clocks changed, before I began cycling in earnest. I work full time, and travel away on business quite a bit. These factors reduce the opportunity I have available for training, so evenings and weekends are prime time really. When I work locally, I cycle to the office, and that clocks up over 100 miles a week.

Last weekend, as the photo shows, I dusted off my trusty mountain bike and cycled in Delamere Forest. This has rekindled my passion for mountain biking, as it is so exhilarating, which will help me get fitter and better prepared for August. Despite my lack of intensive training, I am still confident of completing this challenge, just quietly confident!



My best incentive however, would be if people were to sponsor me, as then I would have to get serious. If no one sponsors me, there's not much point in bothering, is there? If you fancy piling on the pressure, please sponsor me (even just a couple of pounds would help), by visiting my just giving site at [www.justgiving.com/roger-greig](http://www.justgiving.com/roger-greig).

## CARER'S Week

CARER'S Week will take place from 14-20 June 2010.

Thousands of events and activities take place throughout the UK to highlight and celebrate the contribution that carers make. Carers Week will highlight:

- why support of carers is crucial
- how carers miss out on things we all take for granted
- that needs to be changed.

You can find out more at [www.carersweek.org](http://www.carersweek.org)

## Influence a change

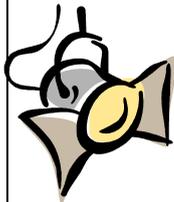
DO you spend several hours a day caring for an adult aged 18 to 65 who is living with motor neurone disease?

Would you like to influence a change in services that allow carers to take a break?

If the answer to both of these questions is 'yes' then we would like to hear from you.

We are a team at King's College London and have been commissioned by the Department of Health to find out about carers need for and experience of respite care.

We would like carers to complete a survey to help us. If you are interested further details are available on our website at [www.kcl.ac.uk/schools/medicine/depts/palliative/arp/eval/carers.html](http://www.kcl.ac.uk/schools/medicine/depts/palliative/arp/eval/carers.html)



# Spotlight on Carer's CARING with Confidence

CARING with Confidence is carrying out an extensive piece of research into the learning and training opportunities for carers in the north west of England.

Phase one will identify carers' attitudes towards the learning and training opportunities they have participated in and what they would like to see more of.

Phase two involves identifying what learning and training opportunities are offered to carers through local organisations and how they can be accessed. This data will also contribute to a new online directory of services which will be launched.

The initial phase of research is focused on carers and organisations based in northwest England before being extended to other parts of the country.

Find out more at [www.caringwithconfidence.net/news/19](http://www.caringwithconfidence.net/news/19)

### Carers UK (England)

Telephone: 0207490 8818

Email: [info@carersuk.org](mailto:info@carersuk.org)

Website: [www.carersuk.org](http://www.carersuk.org)

## Claiming new Carer's Credit

FROM 6 April 2010, the new Carer's Credit will be introduced. It is a National Insurance credit which will enable carers to build up qualifying years for the basic State Pension and additional State Pension.

People will need to apply for this new weekly credit, unless they are in receipt of Income Support (IS)

Those caring for disabled people for 20 hours, or more, a week will be able to get build up Carer's Credit if:

- the person(s) they are looking after receives the middle or highest care component of Disability Living Allowance (DLA) or any rate of Attendance Allowance (AA) or Constant Attendance Allowance (CAA); or;
- the person or persons have been certified by a health or social care professional as needing the level of care being provided.

People will need to apply for this new weekly credit, **unless** they are in receipt of Income Support (IS) because they are substantially engaged in caring, in which case Jobcentre Plus will notify the award of the credits.

Carer's Credit is a new National Insurance credit (**not to be confused with a benefit payment**) will mean thousands more carers will be able to build up their basic State Pension and State Second Pension. Bereavement Benefits for spouses and civil partners will also be protected.

To find out more about Carer's Credit and how to apply go to [www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG\\_1003811](http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG_1003811) or contact the Carer's Allowance Unit on 0845 608 4321)

## Newsletter

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

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

Thank you for your unwanted, unloved soft toys

By Hazel Francis

They will be found a new home at a summer fete in June. I will report back on the success of the fete in the next issue of the newsletter.



Once again thank you to everyone who donated.

## Congratulations



to our Treasurer Martin and his wife

Claire who gave birth to a little boy, George Harry on Easter Sunday, 4<sup>th</sup> April.

He weighed in at 9lb 5oz.

## Financial Stuff

Summarised Accounts for the Year Ending 31st January 2010			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	14,266.29	Financial Support	7,497.70
In Memoriam Donations	2,295.00	National Office	5,783.12
Fund Raising	4,362.92	Branch Admin costs	2,403.71
Bank Interest	16.27	Publicity	1,245.84
Sundries	0.00	Sundry	0.00
		<b>Total Expenditure</b>	<b>16,930.37</b>
		<b>Surplus</b>	<b>4,010.11</b>
<b>Total Income</b>	<b>20,940.48</b>	<b>Total</b>	<b>20,940.48</b>

**Treasurers Report** - The above are the audited accounts for the year ending 31<sup>st</sup> January 2010. There was a 13% fall in Income compared to the previous year. In Memoriam donations have fallen by almost £9000, but this has been partly offset by an increase in General donations of nearly £7000.

A number of fundraising events were held throughout the year, including another successful Strawberry Evening. While Income has fallen 13% Expenditure has fallen 21%. Even though expenditure has fallen we have actually increased our support to those people who are living with MND by £1000.

Approximately £1000 was spent printing and distributing the newsletter in the year, I hope you would agree that raising and maintaining our profile is a good investment for the future.

## Learning about the research we fund

ALL of the research that we fund has a clear therapeutic or clinical relevance to MND and we currently fund over 35 projects. These range from scientific projects based in a laboratory to clinical based projects based in hospitals. But what do these projects really mean for you?

Over the past few months we have been working on the redevelopment of the information sheet that we produce which provides a portfolio of all of the research projects that we currently fund.

Written in an easy-to-read way, we have now sorted the projects that we fund into topics that really mean something to you. The topics are causes, developing treatments, markers of disease progression and healthcare. We hope that this redeveloped information sheet will be able to provide you with a summary of the plethora of research projects that we currently fund.

To download a copy of our latest, January 2010 version of 'Funding MND Research' please visit the research pages [www.mndassociation.org](http://www.mndassociation.org) and click on 'Res Inf E – Funding MND research'.

Alternatively, you can order a paper copy by contacting MND Connect.

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 Motor Neurone Disease.

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

## Branch Contacts

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Treasurer	Martin White	01695 628292	<a href="mailto:martin@mndcheshire.org">martin@mndcheshire.org</a>
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Fund Raising	Hazel Francis	01270 626222	<a href="mailto:hazel@mndcheshire.org">hazel@mndcheshire.org</a>
Association Visitor	Joel Millet	01625 525409	<a href="mailto:joel@mndcheshire.org">joel@mndcheshire.org</a>
Association Visitor	Ann Barlow	01606 891027	<a href="mailto:ann@mndcheshire.org">ann@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