



To Our New Association Visitor

Some of you will have already met Joel Millett at our support meetings, but I can now tell you that Joel has completed his training as an Association Visitor.

Joel says –

“Hello my name is Joel I like to think that I am young, free and single, but in reality I’m 48 and married to my job. Thankfully I love my job and age, well, it’s all in the mind. Along with my 27 colleagues I run the family business, a 250 bed, pet hotel in Wilmslow, Cheshire. Whilst dogs and cats are a huge part of my life I do have other interests, which are eating, drinking and gardening.



Why become an Association Visitor? Well my Mum Erica Millett had Motor Neurone Disease and I was lucky enough to be able to care for her at home for 2 ½ years. Mum was a great believer in life and also in living life to the full whatever your condition. Mum once said “Life can be a challenge, it’s how you deal with it that counts”. We all know that anyone living with MND and their family and friends all go on a huge learning curve. I know I did and I hope that I will be able to use what I learnt in my role as an Association Visitor for the Motor Neurone Disease Association.”

Joel can be contacted on:



01625 525409 (work)



01625 529166



07760 753085

joel@mndcheshire.org

Diary Dates

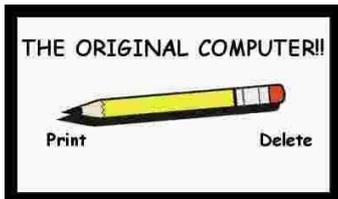
July 9	Strawberry Evening Nantwich CC
Aug 27	Committee Meeting Tarpoley
To be advised	Arley Hall Gardens with Lord Ashbrook
Sept 17/18	Collection at Sainsburys Nantwich

For further details go to
www.mndcheshire.org

Appeal for Friends of the Branch

Could you be our 'Friend'? We are planning to set up a contacts list of 'Friends of the Cheshire Branch' 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 and let us know how you would prefer to be contacted

The Original Computer



Memory was something you lost with age

An application was for employment

A program was a TV show

A cursor used profanity

A keyboard was a piano

A web was a spider's home

A virus was the flu

A CD was a bank account

A hard drive was a long trip on the road

A mouse pad was where a mouse lived

And if you had a 3 inch floppy.

You just hoped nobody ever found out!!

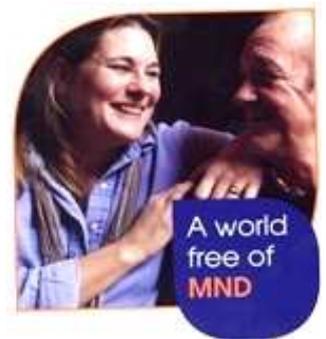
The Spring Conference at the Crowne Plaza, Chester

The conference was well attended, both by professionals and exhibitors and also members of Branches.

The Cheshire Branch was extremely well represented with 14 friends and members off the Branch attending. The facilities at the venue were very good; the hotel had reserved as many spaces as were required for those attendees requiring disabled parking bays.

The conference was well organised, and coupled with the exhibitors very interesting. The first speaker was Dr. Brian Dickie, Director of Research Development, MND Association, it was pitched and delivered at the right level, and was very informative. The presentation was based on two studies on the latest stem cell research which were described at the International Symposium by Prof Nick Maragakis and Prof Clive Svendsen. Although both of these studies are exciting, they are still being tested on animals, so it may be years before they can be tested on plwMND..

The next two presentations given by Heidi Macleod, Director of Care and Development, MND Association, and Sharon Schillerstrom, Care and Development Manager, MND Association, were both in part interactive with the audience. The first presentation was an introduction to personal health budgets, which explained the background and what personal health budgets were. There appeared to be a very mixed reaction from the audience on the pros and cons of this type of funding for people with long term conditions.



The presentation by Sharon was on the Carers Pack which during the next 12 months will be developed by the Association. It will strengthen the Association's commitment to supporting the families and carers of plwMND.

The last speaker was Guiseppa Pennetta, a research scientist from the University of Edinburgh. Her research focuses on understanding the molecular details of MND pathogenesis and on developing neuroprotective therapeutics. To undertake this research she creates genetic models in fruit flies. This experiential approach will rapidly provide a better understanding of the molecular mechanism responsible for MND.

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.



Lantern for Life Gathering

As part of the 30th Anniversary celebrations the Branch will be holding a gathering. The aim is to mark the 6th October, the birthday of the Association with the lighting of lanterns throughout Britain to remember all those lost to the disease and to illustrate our hope for the future. Further details will be sent out nearer the time.

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.

I will take articles in any format and if necessary edit them and get your approval before publication.

So please do submit your contributions and make this newsletter work for everyone in Cheshire

Hints & Tips

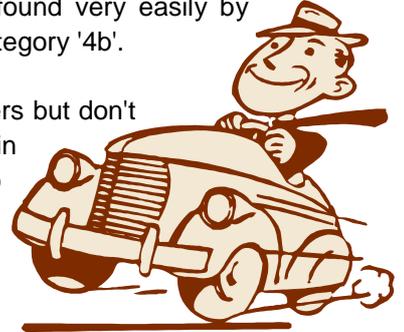
Driving Licence Photo Reminder

PHOTO card driving licences were first introduced into the UK in July 1998, with a requirement that the holder's photo be updated every 10 years.

If you were one of the first to get one of these when they came out remember to check when your photo expires. This information can be found very easily by looking at the front of the card and the date next to category '4b'.

The DVLA is supposed to issue reminders to all drivers but don't rely on them doing so. If you fail to renew your photo in time you risk a fine of up to £1,000. All you need to do to avoid this is send a new photo along with a request for a renewal to the DVLA.

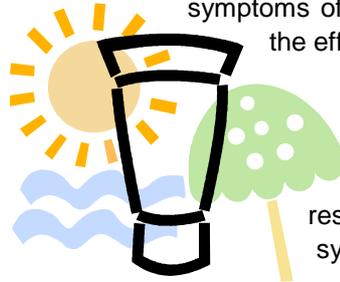
However this amendment service isn't free, you'll have to pay an administration fee of £17.50 but this is small when put it next to the fine you can receive for not having an up to date photo.



Department of Health Advice

Heatwave - a guide to looking after yourself and others during hot weather

The Department of Health (DH) recently published advice and information on the potential hazards of a heatwave. This information includes how to recognise the symptoms of heat exhaustion and heat stroke, and how to deal with the effects of too much heat.



In a severe heatwave some of us may get dehydrated and our bodies may overheat. People living with MND are at greater risk, particularly if you are experiencing respiratory problems, as a severe heatwave may make symptoms worse.

Some medications can also provoke or increase the severity of heatstroke, as they can interfere with regulation of body temperature.

We would encourage you to download a copy of the leaflet from the DH website http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099054

M6toll™

If you have a Blue Badge you are entitled to a toll exemption for your vehicle when using the M6 Toll. The Mobility Exemption Pass allows free passage of the nominated vehicle on the M6 Toll only. The pass which currently costs £15 lasts for 3 years.

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.



The friends and family of Mr and Mrs Sanders held a family day, which is an annual event, to raise money for charity at the Straw Hat Pub in Ellesmere Port on St. Georges Day. The charity nominated this year was the MND Association and raised a total of £450.00 which was donated to the Branch.



Mr and Mrs D I Jones celebrated their golden wedding anniversary in May and donated £500.00 to the Branch in memory of Bea Jones who passed away last year after suffering with MND

Winsford Town Council

The retiring Town Mayor Des Worthington, nominated the MND Association as one of two charities for his year of office which ended on 18th May.

The Branch was invited to attend the Winsford Town Council AGM and Margaret and Hal Bailey represented the Branch at the Meeting.

A cheque was presented to the Branch totalling £3,100 which had been raised at various events over the last 12 months.



The cheque was gratefully received by Margaret and Hal. Des Worthington, who is a long time friend of Trevor Druce one of the Branch's members, said "He had decided to nominate the Motor Neurone Disease Association not only to help those who suffer with the disease but also to increase awareness of the disease"

Hankelow Village Fete

On Sunday 14th June, a glorious sunny day, Hankelow held its annual village fete. Each year they donate the raffle held on the day to charity.

In recognition of one of the villagers Mr Tom Bourne who has been living with Motor Neurone Disease since October 2001 the organisers decided this year to donate 50% of the proceeds from the raffle totalling £500.00 to the Cheshire Branch of the MND Association.



Fete organisers allowed the Branch have a stall free of charge, which was manned by members and friends of the Branch, and we made £55 from the crafts and quality items.

The fete was very well attended with stalls ranging from plants to cakes. There were also activities for the children (and parents) including maypole dancing by Audlem St James School, Musiclands young musicians, and Cheshire Academy Gymnastics, and last but not least the 50 yard dash for young and old

Cheshire FM Radio

The Branch Chair, Julie Williams, was invited to an interview to promote MND Awareness week at Cheshire FM on Thursday 18th June.

Cheshire FM is a local radio station covering Northwich, Winsford & Middlewich area. Everyone at Cheshire FM was so welcoming and the presenter, Big Al and his assistant Jodie, were genuinely interested and appalled that MND doesn't get the attention it deserves. Big Al announced on air that Cheshire FM are now Friends of the Cheshire MND Branch, Jodie also offered to help by distributing leaflets. we would like to say thank you to all at Cheshire FM, especially Big Al and Jodie, for giving us the opportunity to raise awareness through their station.'

Robert to Sail the Atlantic



Robert Shaw first developed symptoms in September 2007 but was not officially diagnosed until June 08. Robert's speech has been affected and he can't actually speak at all now. However, he is continuing with plans to sail across the Atlantic in November as part of the ARC Race (Atlantic Rally for Cruisers) when he will be in charge of all navigation on his 57ft boat. He will be taking part in the 2,600 mile race from Gran Canaria to St Lucia with four other crew members.

Robert does not have a sponsor for the race, the crew is paying for the trip themselves, but they are looking to raise money for MND and all money they raise will go straight to the charity. No one suffering from MND has ever crossed the Atlantic in this way before

Arley Hall Garden Festival

The Arley Garden Festival is now in its 15th year and has slowly become the flagship event in the Arley Calendar and was held on June 27th and 28th.



There were lots of fantastic flower and plant nurseries from all over the country. The floral Marquee was in full bloom with a number of award winning displays on show and available to buy.

Lord and Lady Ashbrook allowed the Branch to set up a stall to promote the Association. The stall was manned by members and friends of the Branch. Although we were primarily there to raise awareness we collected £150.00 from donations and the sale of raffle tickets.

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Festival-goers were also be able to sample the Pimms & Champagne bar, enjoy a barbeque, and indulge with an ice-cream while taking in the sounds of a jazz band.

Northwich Library

Pictured here are Frank and Doreen Casey in front of a display in the entrance to Northwich Library during the MND Awareness Week.



The display was put up to show the people of Northwich and to raise the awareness of MND and the Association at both National and Local level. We received over £30 from donations during the week

Our thanks go to Doreen and Frank once again for organising the stand. If anyone has any ideas for next year please let us know.



in Nantwich

The Walk To D'Feet was held Saturday 27th June as part of the Branch's Awareness Week activities.

We had a total of 40 Walkers, which included people living with MND along with their carers. Some walkers had been sponsored. Refreshments were enjoyed after the walk back at Nantwich Methodist Church. The Methodist Church also had a collection for MND which raised over £80, and provided the use of the Methodist Church facilities which was very supportive.

The Walk To D'Feet has raised over £700 with more donations expected. For pictures and a full account, including the total amount raised please go to www.mndcheshire.org/3.html

Food for thought

Outside a Zoo, there is a car park for 150 cars and 8 coaches.

It was manned by a very pleasant



attendant with a ticket machine charging cars £1 and coaches £5. This parking attendant worked there solid for all of 25 years. Then one day, he just didn't turn up for work.

"Oh well", said the Zoo Management - "we'd better phone up the City Council and get them to send a new parking attendant..."

"Err no", said the Council, "that car park is your responsibility"...

"Err no", said Zoo Management, "the attendant was employed by the City Council, wasn't he?"...

Sitting in his villa in Spain, is a bloke who had been taking the car park fees, estimated at £400 per day at a Zoo for the last 25 years...

Anniversary Activities

2009 is a very special year for us. It's the Association's 30th anniversary - let's mark it together. The Association will be marking the occasion with a number of activities from May-November.

The Association would really like for the whole MND community to come together to mark this very special period in our history. The Association wants to thank our volunteers who work so hard each and every day for people affected by MND and to remember old friends who are dearly missed.



A group of staff and volunteers are working together to come up with a number of activities to mark the 30th anniversary. Obviously it goes without saying that the people who have founded the organisation must take a very special place in the 30th birthday activities.

Day of remembrance Whilst it's important to celebrate how far the Association have come, and the role of our branches and groups the Association feel that it is important that the Association reflect on those the Association have lost.

On 6th October (our actual birthday) at 6pm the Association would like to have a period of remembrance for all those who have lost their lives to MND. This is something everyone can do and unites us in our fight to end this terrible disease. Perhaps you would like to gather together with your branch or group to remember family and friends and pay tribute to them, or maybe you would prefer to pay tribute within your own home. It really doesn't matter - the important thing is that the Association all come together (not necessarily physically) at 6pm.

Pearls of Wisdom As part of our 30th birthday activities the Association will be collecting pearls of wisdom - hints and tips that have made a difference to people's lives over the last 30 years. The Association will be including them in each edition of Thumb Print throughout our 30th year. The Association know that so many of you have come up with innovative solutions to make life more comfortable. Between us the Association must have so much information that if shared could be another tool to help us fight this disease. So please help us by sending in any hints or tips that have helped you, as these may the well be able to help others. Send them to Jenny Saunders, MND Association, PO Box 246, Northampton NN1 2PR or email Jennifer.saunders@mndassociation.org

30 faces of MND During October our the Association website will feature 30 faces of people personally affected by MND over the last 30 years to represent each year of our existence.



To Peg or not to Peg

The first story 'Decision Time' of a trilogy regarding Percutaneous Endostopic Gastrostomy feeding by Frank Casey. The trilogy will cover giving my reasons for having the procedure carried out, with regards to how it will affect Frank and his wife Doreen. For the 1st instalment go to www.mndcheshire.org – Members Forum

Deadlines for the October Newsletter

All stories,
information or
articles to be
received by
19th September

If you require
advice or further
information please
contact Hal Bailey
on 01565 634831
or by email on
hal@mndcheshire.org

**Benefit thieves
We're
closing in**



Financial Stuff

TREASURER'S REPORT AS AT 31 st May 2009			
Income		Expenditure	
Item	Year to Date	Item	Year to Date
General Donations	8,345.55	Financial Support	2,394.64
In Memoriam Donations	1,180.00	National Office	5,783.12
Fund Raising	0.00	Branch Admin costs	530.97
Bank Interest	16.27	Publicity	278.77
Sundries	6.23	Sundry	170.85
		Total Expenditure	9,158.35
		Surplus	389.70
Total Income	9,548.05	Total	9,548.05

Research Funded by the Association

Are you interested in reading more about the research that we help to fund?

Research Information Sheet E has now been updated to include the research projects that were accepted for funding in October 2008 as well as the Lady Edith Wolfson Clinical Research Fellowships and the lithium clinical trial.

This information sheet can be downloaded on the research pages of our website. www.mndassociation.org/research/research_we_fund/ Alternatively, if you would like to receive a hard copy of this information sheet then please contact MND Connect.

The World of Finance Explained

Young Chuck moved to Texas and bought a donkey from a farmer for \$100. The farmer agreed to deliver the donkey the next day. The next day the farmer drove up and said, "Sorry Chuck, but I have some bad news. The donkey died last night." Chuck replied, "Well then, just give me my money back." The farmer said, "Can't do that. I went and spent it already." Chuck said, "OK, then, just bring me the dead donkey." The farmer asked, "What ya gonna do with a dead donkey?" Chuck said, "I'm going to raffle him off." The farmer said, "You can't raffle off a dead donkey!" Chuck said, "Sure I can. Watch me. I just won't tell anybody he's dead." A month later, the farmer met up with Chuck and asked, "What happened with that dead donkey?" Chuck said, "I raffled him off. I sold 500 tickets at two dollars apiece and made a profit of \$898.00." The farmer said, "Didn't anyone complain?" Chuck said, "Just the guy who won. So I gave him his two dollars back."



Chuck now works for AIG.

Useful Contacts

**MND
connect**
08457 626262
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 Motor Neurone Disease. She can be contacted on 0845 375 1832, or email: kathy.james@mndassociation.org

Branch Contacts

Secretary	Clare Ward	01565 653475	clare@mndcheshire.org
Treasurer	Martin White	01695 628292	martin@mndcheshire.org
Branch Contact	Marion Chadwick	07929 732958	marion.chadwick1@tesco.net
Publicity Officer	Helen Parker	07834 773113	helenswords@sky.com
Newsletter Editor	Hal Bailey	01565 634831	hal@mndcheshire.org
Fund Raising	Hazel Francis	01270 626222	hazel.francis@cheshire.gov.uk

Important Notice

If anyone knows a local shop or other retail outlet then please get in touch with Hazel either by phone or email. We have a number of collection boxes collecting dust in garages or bedrooms, rather than cash,. The only proviso is that the Branch needs full details of where they are going to be situated prior to issuing the collection box



If you would like to receive your newsletter by email, please contact Hal Bailey on hal@mndcheshire.org

Motor Neurone Disease Association, Registered Charity Number 294354.