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Reading and West Berkshire Branch

www.mndrdgwberks.freeuk.com

In this issue

Anna's Sahara Trek	2
OSCARR Award for Branch	2
Another Cash Boost from Sam's Bravery	3
Best Friends' Runaway Success Story	3
Neuro Nurse's Impact	4
MND Study Day	5
Our Holiday in Abruzzo by Roland Lewis	6
Treasure Seekers Strike Gold Again	7
Forthcoming Events Open Meeting Invitation	8

MP BACKS MND RESEARCH

Reading East MP Rob Wilson has pledged his support to our campaign for more funds to help free the world of MND.

He called on Government cash to be given to research into the cause of motor neurone disease following his visit to the branch's summer tea party in Caversham.

The MP dropped in on the riverside event at Reading Canoe Club on The Warren and spent time talking to people living with the disease, their carers and Association volunteers.

Mr Wilson said, "MND is one of those illnesses that doesn't receive the attention that it deserves and I want to try and use whatever influence I have to highlight it."

The Tory MP is already a member of the All Party parliamentary Group on MND which meets several times a year to discuss current issues on the disease.

Liberal MP Lembit Opik, whose father died from MND, has enlisted the support of both Tony Blair and Gordon Brown since he became our president and the Association is entering into a new and exciting phase of work



Rob Wilson is pictured (centre) chatting with two of his constituents, Roland Lewis, who is living with MND, and Branch chair Margaret Moss.

with the Medical Research Council to jointly fund research.

Mr Wilson told guests at the tea party he fully supported the Association's campaign to raise £7.5 million from private donors and £7.5 million matched-funding from Government.

Funds from private donors, including major pledges of £1 million and £2.3million respectively, mean that we are making good headway towards our target.

Contributed by Jane Gilbert

OSCARR for Awareness Raising

Our local Branch was presented with an OSCARR award by Association President, Lembit Opik, MP, at the 22nd National AGM, Conference and Dinner recently. The Branch was nominated for the OSCARR by Dr. Paul Wicks, who carried out the research on the football cluster in our area. He commented,

"Without the hard work of the Reading branch, this cluster would never have come to light and we would certainly have not been able to coordinate the logistics required to study these delightful gentlemen. For several weeks their actions lead to national attention for Motor Neurone Disease and the work of the Association."

More on this story on page 2.....



Branch Chair, Margaret Moss, receives the OSCARR award from Kirstine Knox, National Office Chief Executive and Alan Graham, Chair of Trustees.



Anna's Sahara Trek

Henley girl Anna Cheetham is preparing for the trek of a lifetime this month (November) in the searing heat of the Sahara Desert.

The plucky 24-year-old has taken on the challenge in memory of her dad Rex Cheetham who died from MND when she was just 18.

Now she wants to raise £2,150 from the MND Association-run trek to help people living with what she describes as "a terrible life-destroying disease".

Anna was brought up single-handedly by her father after her mother died when she was seven. In 1999 Rex married Gill, our Branch Events organiser, but this new-found happiness was short-lived when he died in 2001.

During his illness the Association worked tirelessly to make Rex and his family's life more bearable.

Anna told the Henley Standard in



a recent report on her trek plans: "Without them the struggle would have been intolerable."

The heat is now on for Anna, who works caring for adults with learning disabilities, as the 84 km challenge starts on November 17 and she still needs more cash to reach her target.

You can pledge financial support online at www.justgiving.com/annacheetham or direct through Gill Cheetham.

Anna has been helped to prepare for the searing heat and demanding desert terrain of the Sahara by the team at LA Fitness who are pictured with her at the gym. *(Photo courtesy of The Henley Standard)*

Contributed by Jane Gilbert

An amazing £15,707.50 is the total value of the cards sold in Cards for Good Causes venues across the country in 2006. This is over £5,000 more than the previous year.

The MND Association was lucky enough to be invited as a guest charity in 26 shops – this too was an increase on 2005.

Thank you very much to everyone who gave up their time to volunteer on behalf of the Association and made this happen.

Thank you – 15,707 times!

We are now recruiting for 2007 as the Association's participation in the scheme is dependent on being able to provide a minimum of one volunteer, for a morning or afternoon per week, for each shop where our cards are being sold. The venues usually open mid to the end of October until the week before Christmas.

If you would like to volunteer at Newbury, Reading or Henley on Thames shops please contact Sarah Mayes at national office on 01604 611825.

Unfortunately as a guest charity we have to be invited into the venues and cannot request a certain location. Sarah apologises if your local venue is not listed but says we are being added to more venues every year so watch this space . . .

Contributed by Jane Gilbert

Local Branch receives OSCARR

The OSCARR (Outstanding Support, Care, Awareness and Revenue Raising) for Awareness Raising was presented to Reading and West Berkshire Branch by Association President, Lembit Opik, MP, recently. He thanked all the volunteers for their hard work and commitment over the last 12 months.

The Branch were nominated for this award by Colin Moss, PLwMND and Dr Paul Wicks who, in association with Dr Al-Chalabi, carried out research into the cluster of footballers in

our area. All these footballers had MND at the same time and had played together in Sunday League Teams in West Berkshire in their younger days. They had also reported their own suspicions in our Newsletter.

In nominating us for the award, Dr. Wicks said,

"When our (research) paper was released, the story was on the front page of several local newspapers, page 6 of The Sun, the online versions of several national newspapers, as well as television coverage on ITV and Sky News."

How the story hit the headlines



Accepting the Award, local Branch Chair, Margaret Moss said,

"I was proud and delighted to accept this award on the branch's behalf; many people in the branch worked hard during Paul Wick's research time and subsequently when his paper was published, it is they who won the award!"

Contributed by Margaret Moss

ANOTHER CASH BOOST FROM SAM'S BRAVERY



Duncan Fowler presents the cheque to Jane Gilbert watched by Sam and his wife Anna at their home.

Kingsclere's Sam Brown has inspired another cash windfall for the charity that supports him.

Safety conscious electricity workers decided to make a donation to the Motor Neurone Disease Association after hearing about

how he manages living with a terminal illness.

His son-in-law Duncan Fowler had told his colleagues at Scottish and Southern Energy's Melksham depot about Sam's ten-year battle against the progressive disease.

The workers then chose the charity to benefit from a £750 donation raised under a scheme by which the electricity company rewards a good safety record and lack of accident claims made during the year.

Father-of-three Duncan, who also lives at Kingsclere, presented the cheque for £750 to Jane Gilbert, publicity officer for the MND Association's Reading and West Berkshire branch.

Describing Sam as an "amazing" man, his daughter Heidi Fowler, a teaching

assistant at Kingsclere Primary School said: "He has coped with the progression of the disease really well – he's cheerful all the time."

Wheelchair-bound Sam, aged 63, can no longer speak and uses an electronic keyboard to communicate but despite his disability he still manages to enjoy his passion for pigeon racing.

A former amateur footballer Sam hit the headlines in the Spring when he featured in the King's College London study on MND and possible links with football. He is the only survivor among three local players in the study who all developed the disease simultaneously. The study called for more research into the causes of MND which has no known cure and features in our OSCARR award story in this edition.

Contributed by Jane Gilbert

Best Friends' Runaway Success Story

Two reluctant runners took on a daunting half marathon to help raise money for a charity close to their hearts.

Best friends Gemma Hammond and Lauren Burbidge, both aged 24, amazed their families in Hungerford with their fantastic fundraising efforts.

Afterwards they modestly declared: "We are probably the unfittest pair ever".

Now they have proudly presented their £1,400 sponsorship to the Motor Neurone Disease Association – the charity which supported Gemma's mum Gaie.



Gaie Hammond

Gaie Hammond was a school meals supervisor at John O'Gaunt School in Hungerford and a cleaner at a house in Chilton Foliat until she could no longer carry on working.

She died last year, aged 58. The popular mother-of-three girls first lost her speech and then her limbs became affected by MND.

Her husband Alan, aged 63, gave up his job in Newbury to care for Gaie who was supported throughout her illness by Association visitor Joanna Knott.

He said the girls' fundraising was their way of giving something back to the MND Association.

Gemma and Lauren, who live near each other in De Montfort Grove, presented the cheque to Joanna who was very impressed with their efforts.

"I think it's remarkable", she said after hearing how the pair took on the challenge of the Reading Half Marathon.

Gemma, who works in Inklings in the High Street, and Lauren, a dispenser



Joanna Knott receives the cheque from Gemma and Lauren

at Boots in Newbury, admit they did very little training.

After three hours and thirty three minutes they walked across the finishing line together and smashed their fundraising target of £1,000.

"We did beat the Sumo wrestlers!" they both declared vowing never to attempt a half marathon again.

Contributed by Jane Gilbert

Our Neuro Nurse's Impact

As we go to print, it is two years since the Specialist Nurse post was established, thanks to the huge efforts and generosity of members and friends. The Branch was also able to share the funding with the West Berkshire Neurological Alliance (WBNA) for this ground breaking post and it is a fantastic achievement!

The post was to be a 'Pilot' to see if it proved itself so that the NHS Primary Care Trust (PCT) would establish it as a permanent post. Now that the 'pilot' has run its course, the good news is that Berkshire West PCT has taken it on, at the moment, till the end of the financial year (end of March). This five months gives them time to arrange the funding to establish the post permanently.

The report from an independent expert which measured the effect the nurse had had on those living with

neuro conditions (the 'Impact Study'), proved that significant financial savings over and above the costs of the post had been made, and this was instrumental in the PCT's decision. It showed what we all already knew – that this Specialist Nurse has brought *huge* benefits, not only to those with MND, but also to those with other complex neurological disorders such as Huntington's Disease, late Effects of Polio and others.

We pay tribute to the 'person' too – our own Specialist Nurse Carol Allen, who, besides dedicatedly carrying out her professional role, has added her own personality, time and devotion! Thank you Carol, especially from all those who live, or have lived with MND and, of course, from the Branch as a whole. It's so wonderful to know that the post is secure!



Specialist Neuro Nurse, Carol Allen, visiting Mrs Anne Smith, who is living with MND, at her Thatcham home in 2006

Tributes and thanks

...to many people for this successful outcome – Carol herself of course, but also to John Holt of WBNA and Prof. Christine Collin.

Also to our own Monnica Stewart, committee member, Association Visitor and our guiding light who cornered the committee and initiated our involvement in no uncertain manner!



Thank you again Monnica!

Monnica is pictured at her 80th birthday in 2004

And how it all started...

Are the origins of this story a little lost in the mists of time? Can I take this opportunity to retell the tale?

In the beginning some members of the WBNA and the MND branch had a dream – that what's needed is someone who can fill the gaps in the community as well as at clinics after diagnosis. Wholehearted support was immediate from Prof. Christine Collin.

Raised at several branch committee meetings, heads nodded each time until Dr Monnica Stewart became

impatient with the lack of decision, and said as much! Whereupon the Committee agreed to support WBNA's initiative and to raise funds specifically for this purpose - and with National Office's approval.

Monnica died in October 2004 (three years ago as I write) and in her memory the branch set up the Monnica Stewart Neurological Nurse Appeal. It was quite amazing to see the response from the branch in funds raised and support for the idea.

A Steering Committee was established, under John Holt's excellent and inspired leadership, and eventually the Job Description etc was written, RBH approval obtained, the post advertised and subsequently filled. Carol was in post and the work could begin!

Such an exciting result, to see and hear of the difference the dream had made!

Articles contributed by Margaret Moss

MND STUDY DAY A SUCCESS

The Thames Valley MND Network is a group of four specialist nurses, including our own Carol Allen, who cover the whole of the Thames Valley, caring for people with MND and other neurological conditions. They decided to hold a study day concentrating on MND at the Newbury Race Course Conference Centre on 17 October.

As you know, motor neurone disease is a devastating and fatal condition, with no known cure. Its frequently rapid progression leaves people unable to walk, talk or do the everyday things which most of us take for granted.

Caring for a person with MND & their family can be daunting for professionals and stretch the processes of service provision. This study day provided an opportunity for professionals in the field to find out more about the condition and recent developments in treatment & care; to identify other professionals & organisations involved & find out how they could help each other; to share common experiences & discuss ethical issues.

Speakers included local consultants in neuro-rehabilitation and respiratory medicine, a speech & language therapist, community dietician and PEG liaison nurse specialist.

Members of the MND Connect team also came to support the day. Over 70 professionals in their field, coming from London to Luton, Banbury to Basingstoke, braved the notorious traffic jams in this area to attend on a beautiful, crisp Autumn day.

Newbury Race Course provided all their facilities free of charge, including a conference room with a beautiful view over the countryside. In the words of Richard Coleman, Chair of the South Bucks Branch, it was 'an excellent day'.

In addition to Newbury Race Course, the nurses of the Thames Valley MND Network would like particularly to thank the following individuals and organisations for their generous support in helping to make this a successful day: the speakers, for making time in their busy schedules to address the delegates; local branches of MND Association for both financial and administrative support; equipment suppliers ResMed (non-invasive ventilation) and Abbotts (nutritional advisor) for providing displays and staff to explain their products and offer advice on its use; Waitrose and Marks & Spencer for their donation towards the gift presented to each speaker; finally, Sun Mobility, a local supplier of disability & mobility products, for their generous donation of £200.

The nurses are considering another study day focusing on the person living with MND, quality of life issues, symptom management, advanced directives/living wills and more. If you would be interested in attending, contact Carol Allen on 0118 3228707 or carol.allen@royalberkshire.nhs.uk so that she can let you know when this is organised

Contributed by Val Pearson



Thank you to Sun Mobility (based at ASDA) for their £200 sponsorship of the MND Study Day.

For more information on mobility products, visit:
www.morethanmobility.co.uk



It's that time of year again! The MNDA Christmas Card catalogue can be viewed on-line at www.mndassociation.org/shop OR get your Christmas Catalogue from: Val Pearson, 3 Mount Pleasant, Wokingham, Berks RG41 2YG, Tel: 0118 9789063; e-mail: valerie.a.pearson@btinternet.com

Remember, if you order cards through the branch for your family and friends, we can claim 20% of the selling price for branch funds to use for the benefit of local people living with MND— just give your order to Val with your cheque made out to MNDA. The Branch will then place the order for you and make sure the cards reach you in good time.

We will also be selling cards again this year at both the Pangbourne and Wokingham Christmas Fairs during November/December (Pangbourne on Sat 3 November; Wokingham on Sun 2 Dec).

In June we decided to go for a short holiday in Italy. My partner Jennifer had been urging me to go to Umbria or Tuscany for a number of years and I had been resisting because I thought the area might be too touristy (we like quiet mountain scenery). I had heard good things of Abruzzo - it has 3 National Parks, hundreds of miles of sandy beaches, lots of hill top villages and the Apennine Mountains with the highest peak in Italy, south of the Alps, in Como Grande, at 2,912 m above sea level.



Como Grande and Roland in L'Aquila with A b r u z z o National Park below



I had printed a route map from the airport to our first hotel. Luckily, we spotted a parked police car and managed to make them understand our problem. Next thing we know is that we are following them to our hotel where we arrived 20 minutes later. There were many thank-yous, handshakes and prolonged farewells!

The only down side of the holiday was disabled car parking. We had taken our Blue Badge but never had the opportunity to use it.

OUR HOLIDAY IN ABRUZZO

by Roland Lewis

The following is one person's view of Abruzzo which describes it very well:-

"I don't think you can compare Abruzzo with Umbria. As beautiful as Umbria may be, Abruzzo is much more remote and wild. It is one of the most unspoilt regions in Italy with a focus on nature. There are some lovely medieval villages there like Santo Stefano di Sessano... I can absolutely recommend it if you're in search of an off-the beaten path area in Italy."



We like to plan our accommodation before we go although there is no need in Abruzzo in June -don't holiday there at all in July/August because it is too crowded and hot. You can fly to Pescara on the Italian east coast (the Adriatic) or to Rome on the west coast, and it is about 1 hour from either by car on the autostrada to the Apennine Mountains. In the end, we flew to Pescara from Stansted because the flight times were friendly.

There were plenty of well placed disabled spots but they were all full of cars with no Blue Badges.

My best part of the holiday was up in the mountains on the Campo Imperatore plateau having a sandwich and a coffee in the sun at a refuge. Jen liked the unspoilt hill top villages such as Atri, Penne, Scanno and Loreto Aprutino. Pescasseroli, capital of Parco Nazionale d'Abruzzo and Lazio e Molise are delightful. L'Aquila, the capital of Abruzzo, is also well worth visiting.

Roland adds these few words about himself:

Born in 1949, I was diagnosed with Progressive Muscular Atrophy (PMA) in 1999. I have been a keen sportsman all my life. I have two grown up children and just the one (indispensable) partner. I stopped working (as a Computer Consultant) in October 2003 and have been on many holidays since then.

I feel very fortunate in having PMA rather than MND/ALS. I believe in being positive and I look forward to the future. I am still able to walk although I have to be careful. My arms and hands are very weak so I can only manage *low* rather than *high* fives.

We booked everything over the internet and it was very easy. We asked for rooms suitable for a disabled person and were very pleasantly surprised. (Roland plans to offer some hints and tips in a future Newsletter article on booking holidays for disabled people over the internet).

We had a lovely holiday with hardly any rain. The countryside was very green everywhere with lots of flowers, very few tourists about , little English spoken and empty hotels. We found Italian driving was very good but the mountain roads were tiring. We got lost leaving the airport even though



They kept it quiet, but here they are: Roland and Jennifer, with Roland's children, David and Mari, at their wedding on 30th September — Congratulations and best wishes from all of us!

TREASURE SEEKERS STRIKE GOLD AGAIN

Treasure hunters have struck gold again for the Motor Neurone Disease Association.

A second metal detecting rally in fields on the historic Englefield Estate, near Reading, has yielded £3,000 for the Branch coffers as well as many ancient items.

Two superb gold coins were the top finds discovered after around 300 enthusiasts armed with metal detectors arrived to sweep as many acres of prime farmland owned by Newbury MP Richard Benyon.

One coin was an Iron Age gold quarter stater, the other an equally fine gold quarter noble from the reign of Edward III.

A bronze statue of Neptune was also dug up but the organisers doubt that it is Roman.

Wessex Metal Detecting Association chairman Jim Bradshaw said: "I'm not too happy with the provenance of the statue. To start with it hasn't been in the soil for long – it's far too clean. Also it has traces of paint which would indicate that it's a recent loss."

The mystery was one of many fascinating elements throughout the sunny September day as finds continued to come in from the fields. Jim said by the end of the rally the experts had recorded or displayed more than one hundred items from Iron Age to Modern. There were Roman brooches and coins, several

Saxon pieces and a selection of Medieval and Tudor hammered silver coins.

He wrote in *The Searcher* magazine: "We are really grateful to the Benyon estate for allowing the rally to take place and to Lady Hallifax of the Motor Neurone Disease Association for her help with the organisation."

One couple, Pete and Jackie McClelland, travelled from Solihull to take part as it was raising funds for MND. Pete's father had died, aged 89, exactly ten years ago to the day after a ten-year journey. At the time he was the oldest person to be diagnosed with the disease.

Two years ago the group's first Englefield rally in aid of the MND Association netted £3,493 in glittering new funds as well as real treasure. Bronze age ring money found there was later declared treasure after an inquest and the finder shared the value with the landowner.

Both rallies were a tribute to fellow enthusiast George Pearce who died, aged 56, from MND in 2005. One of his last wishes was that the club should organise a rally on behalf of the MND Association which supported him and his family.

Branch chair Margaret Moss declared this year's donation from the club as "an absolutely amazing result." She added: "The atmosphere was great and it was so fascinating."

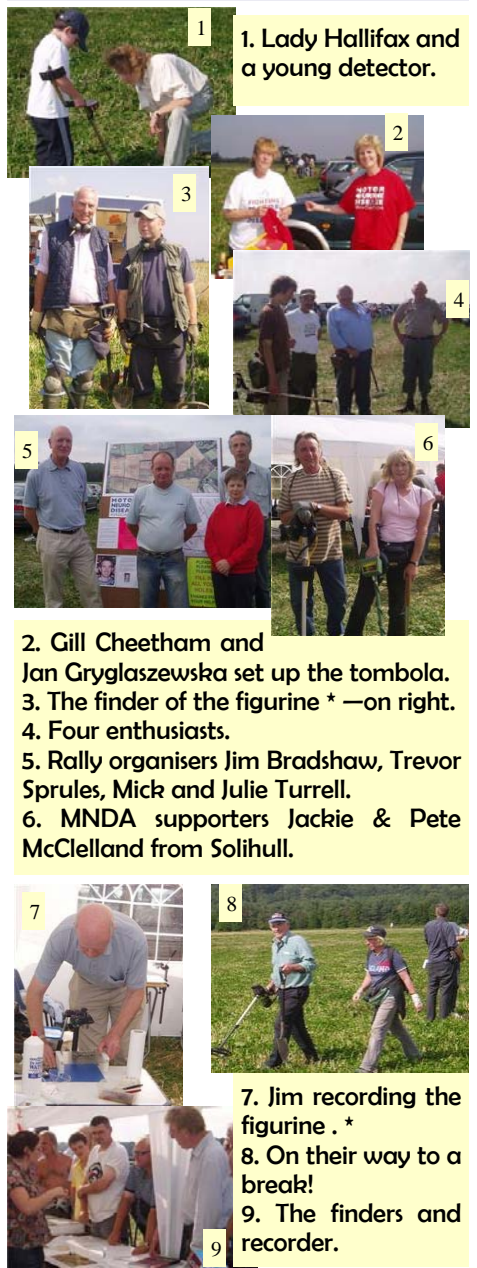
Volunteers from the branch also ran a tombola stall at the rally which collected £128.

Contributed by Jane Gilbert

Some of the exciting finds...



...and memories of the day



1. Lady Hallifax and a young detector.
 2. Gill Cheetham and Jan Gryglaszewska set up the tombola.
 3. The finder of the figurine * —on right.
 4. Four enthusiasts.
 5. Rally organisers Jim Bradshaw, Trevor Sprules, Mick and Julie Turrell.
 6. MNDA supporters Jackie & Pete McClelland from Solihull.
 7. Jim recording the figurine . *
 8. On their way to a break!
 9. The finders and recorder.

DIGGING UP A DINOSAUR



You are warmly invited to :

An Open Meeting

at The Holiday Inn,
Padworth Lane, Bath Road, near Reading,

on Wednesday 21 November 2007

from 7.30-9.30pm.

Speaker:

Adrian Doyle, a Conservator/Preparator/Replicator
from the Department of Palaeontology at the
Natural History Museum



About Adrian Doyle:

Adrian is one of the people who was involved in an exciting project in 1983 to excavate in the field a dinosaur known as Baryonyx, meaning 'heavy claw'. It was discovered by an amateur fossil hunter who came across an enormous claw sticking out of the side of a clay pit, Smokejacks Pit, near Dorking in Surrey.

Adrian worked alongside other museum staff for 10 years on exposing dinosaur bone in the museum's palaeontology laboratory and finally making a replica of the dinosaur for the museum's galleries.

Adrian will be bringing along and demonstrating some of the tools and equipment which were used to remove the hard matrix from around the bone as well as some of his technical work drawings, photographs and slides and other ephemera associated with the project. This will be an informal presentation with the opportunity to handle and experiment with some of the tools and possibly some replica dinosaur material.

A rare opportunity—don't miss it!

The Holiday Inn, previously Courtyard Marriott, is situated on the A4 between Theale and Thatcham. The venue has wheelchair access and toilet. There is a car park on site.

Please contact Val Pearson, Secretary, on 0118 9789063 if you have any queries or need directions.

Forthcoming Events

Pangbourne Christmas Fair
Pangbourne Church Hall

Sat
3rd November
11am-3pm

Drop-in Meeting
Mansion House, Prospect Park,
Reading

Thurs
8th November
6.30-9pm

Open Meeting
Care Services Improvement Partnership
(CSIP), SE Region, St Joseph's RC Church
Hall, London Road, Newbury

Thurs
8th November
1.45 for 2pm

Speaker: Robyn Neonan—The Work of CSIP.

Open Meeting
Holiday Inn, Bath Road, Reading

Wed
21st November
7.30-9.30pm

Speaker: Adrian Doyle—Digging up a Dinosaur

Wokingham Christmas Carnival
Wokingham Town Centre

Sun
2nd December
All Day

Christmas Tea Party
St. Luke's Church Hall, Theale

Wed
12th December
2.30-4.30pm

Thatcham Street Collection
Kingsland Centre, Thatcham

Can you help? Please contact Gill Cheetham.

Fri
14th December
10am-6pm

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Contact Details

Branch Contact
Beth Drury
0118 9421600

Secretary
Val Pearson
0118 9789063

Website
Mary Davidson
mary@rfdq.org.uk

Chair
Margaret Moss
0118 9470871

Publicity
Jane Gilbert
0118 9714172

Events Coordinator
Gill Cheetham
01344 423440

Treasurer
Ed Gryglaszewski
0118 9789069

Newsletter
Mary Watson
0118 9722506

Reg. Care Advisor
MND Connect
08457 626262

