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mnda motor neurone disease association

Reading and West Berkshire

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News Letter

Tennis Mascot Seán's dream day



Ten-year-old Seán Tierney will never forget the day he walked out on court with world famous tennis star Richard Gasquet.

The Marlow schoolboy was one of 34 children, who have been affected by MND, chosen to represent the Motor Neurone Disease Association at the ATP World Tour Tennis Finals at London's O2 Arena.

Seán, whose grandpa Michael Tierney, from Whitchurch-on-Thames, near Pangbourne, is living with MND, was thrilled with his starring role.

His dad Andrew Tierney said: " Seán had a great day and was very excited to walk out with Richard Gasquet. His Mum, Helen, brother Conor and I were there to support him and all cheered for Gasquet in a very exciting match."

Event sponsors Barclays provided the opportunity for the young MND mascots, aged between six and ten, to honour the contribution of former ATP chairman Brad Drewitt, who died last May after battling the disease.

Watched by millions around the world the mascots carried a large tennis ball with the MND Association logo on as they accompanied famous tennis players on to the court and were kitted out in Lacoste tennis wear which they were able to keep after the event.

Seán's grandma, Mrs Marjorie Tierney, said the family were all very happy for their young MND mascot.

"It was tremendously exciting for him - he loved it!.

Jane Gilbert

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LOUISE'S BIG BIKE CHALLENGE

Driving rain didn't deter Louise Brind from completing her 30-mile cycle challenge from Newbury to Bracknell to raise funds for the MND Association.

The 46-year-old from Curridge, near Newbury, was still smiling at the end of her marathon and was delighted to have raised £495 from her efforts.

She decided to raise funds for the branch as a tribute to her uncle Tony Page, aged 67, from Upper Bucklebury, who is living with MND. His wife Carol said the family find it so devastating that they want to do whatever they can to raise funds for people living with the disease.

Louise's ride was part of Vodafone's Big Bike Challenge which aims to raise charity funds via the company's JustTextGiving service, part of the Employee £100 Challenge, open to all Vodafone employees.

Each Vodafone staff member who raises £100 by text, for a charity of their choice, will have that amount matched by the Vodafone Foundation.

Louise, who is PA to the firm's HR director, also hopes to be able to get match funding to boost her total.



Louise is pictured before setting off from Vodafone's Newbury HQ.

"Whilst I was still smiling at the end ... I was rather drenched ... so haven't included a photo of the finish," she said.

Jane Gilbert

NEUROLOGICAL REHABILITATION CONFERENCE

'Facts, Fears and the Future'

The West Berkshire Neurological Alliance (WBNA) is putting on a one day conference entitled '**Neuro-rehabilitation: Facts, Fears and the Future**' to be held at De Vere Wokefield Park Conference Centre near Reading on Thursday, 6th March 2014. This is being organised in conjunction with Dr Faraz Jeddi, Consultant in Neuro Rehabilitation Medicine at the Royal Berkshire NHS Foundation Trust.

The event is aimed at patients, carers and professionals from both Berkshire and all surrounding areas, and will encompass both an exciting line-up of eminent speakers plus workshops and an exhibition of products and services used in neuro-rehabilitation. The closing speech will be made by Francesca Martinez, the popular comedienne, actress and writer, bringing her own special brand of insight and humour to the occasion.

Places are available at £20 each for patients, carers and those from the voluntary sector and £100 each for health and care professionals with these charges including all refreshments and a buffet lunch.

To register, contact Mondale Events
Tel: 01635 573555
Email: info@mondale-events.co.uk
Web: www.mondale-events.co.uk

MND ALERT CARD

AN MND Alert Card is being printed by the Association for use by people with MND, following a successful pilot at St Barts Hospital, London.

It is credit card sized to fit into a wallet, purse or pocket. If a person with MND is admitted to hospital for emergency treatment, the card informs the staff they have MND and need specialist help.

The individual records their name, NHS number and key contacts on the card so that the hospital can access information and make the necessary arrangements as quickly as possible.

Some hospitals may have their own preferred emergency card systems, but the new MND Alert Card can be used if not, and is specific to MND.

People living with or affected by MND can order from MND Connect, on 08457 626262.

IT WAS GRIM!

It was meant to be grim and downright dirty but the 8-mile off-road challenge to run, wade or crawl through mud did not deter a young Berkshire woman from raising money for the MND Association.

Teacher Carly Bidwell took on the Aldershot Grim over the Army's vehicle testing tracks in memory of Tracee Griggs, the mother of two of her pupils at The Emmbrook School, Wokingham.

She said: "I ran the race as I teach Tracee's sons Daniel and Jamie and Daniel asked me to raise money in his mother's memory.

"We raised cash in sponsorship as well as a bake sale – students, parents and staff members all donated to show their support."

The Grim challenge involved short but steep hills, assault courses, uneven paths and lots of mud!

Miss Bidwell said: "At some point the mud was up to my armpits as were the puddles we ran through. They were the hardest bits as it was difficult to get through and when you were out it was almost too cold to keep running. There were also camouflage nets that you had to crawl through to make sure that you got super muddy."

Although it was tough, Miss Bidwell, who teaches history, was spurred on by the hundreds of competitors running for different charities in the "feel good event" last November.

She finished the challenge with a time of 01.45.43 and hopes to have raised about £300 in total for the branch which supported Tracee during her battle with MND. Some of the pledges were made on an online fundraising page set up by Tracee's husband Andy who used his recent 50th birthday party to appeal for donations in lieu of presents.

Miss Bidwell added: "I run a lot of races and am happy to run with the MND running vest on in future."

Jane Gilbert



Grim Survivor Carly Bidwell



Tracee Griggs with husband Andy and sons Daniel and Jamie

WISH LIST

I am always on the look out for new stock - unwanted craft items, wool, stuffing etc, unwanted gifts or anything that I can use on the many stalls I have throughout the year. You may be surprised to know that chipped or odd china, broken, damaged or unwanted items of jewellery can all be used. The list is endless.

If/when you sort through cupboards and drawers - please do not throw items away. Remember that I do car boot sales throughout the year. Having recently lost my dad, my two sisters would have thrown masses of his used, unwanted items away. I asked them if I might have them. There have been many boxes of items, and all are being car booted. Naturally we have kept sentimental items, but all the rest is helping us to raise money.

You can contact me by email me on rlp.jenkins@tiscali.co.uk or by phone on 01189412738.

Lin Jenkins

ROCKING FOR MND FUNDS

An impressive gig by a talented West-Berkshire-based rock band has raised £700 for a cause close to their hearts.

For Fragile's founder member Tom Dawe is living with motor neurone disease and travelled from his home in Surrey to be in the audience at The Croft Hall in Hungerford on January 19th.

Tom, who played guitar with the band since it formed in 1998 as a tribute to '70s rock legends "Yes", was diagnosed with MND at the end of 2012 and was visibly touched by his friends' amazing support.

His journey with the disease has inspired band leader Max Hunt to organise the gig as one of two fundraisers this year for the Motor Neurone Disease Association.

Keyboard player Max, who lives at Hampstead Marshall, near Newbury, knows too well the devastating effects of MND as he lost his mother, Pamela, and several other close family members to the progressive disease which has no known cure. Pamela, who died aged 65, in 2006 had been supported by the Association's Reading and West Berkshire branch.

Now Max and his brother, Nick, also from Newbury, have agreed to take part in a screening programme to help with work at the Oxford MND Care and Research Centre in April as they are potentially at risk from a rare familial type of the disease.

Max, a session musician who has appeared with members of Yes and also Fish, ex-lead singer of Marilion, said of Tom's illness: "It is terrible for him and we are very aware that nowhere near as much priority is given to funding of the MND Association as compared with other health charities.



Thumbs up from Tom Dawe

"With my family history and Tom's links we want to do a couple of fundraisers this year including a larger multi-band event this June in Surrey where Tom lives."

Max, aged 47, a keyboard player and vocalist, was joined on stage for the gig by singer songwriter Claire Hamill and band members Oliver Day, Martin Clark and Russ Wilson.

He told the audience: "Tom will tell you of the great work of the MND Association helping sufferers and their carers cope with life facing this terrible disease."

Max also thanked Dave and Helen Maggs of West Berkshire Brewery for generously donating a barrel of beer for sale during the evening.

Jane Gilbert

Jenko and The Bear are off again

Having got over their 87 mile walk along The Ridgeway, Paul & Ross Jenkins will be tackling the same distance, along the Kennet & Avon Canal this summer, starting from Bath and ending at Reading.

We would like to invite people to join in again this year, but I think it put some people off because they walk so fast (and so far) each day. Please don't feel that you have to keep pace with them. Why not start one day with them, then meander along at your own pace, enjoying the wonderful scenery? Alternatively, meet them for lunch one day and start the afternoon in their wake. For those less active, it is always nice to see friendly faces along the way, or sharing a picnic lunch.

They will be setting off on Sunday 17th August, and finishing in Reading on Thursday 21st August.

Sheila and I will be "struggling along in the support car" each day. We might find time to do a bit of sight seeing, or shopping, and I'm sure we will be able to manage an ice cream or two along the way!

We have already started raising funds towards this walk, and already have £464.00 in the kitty!

If you would like further details please email: rlp.jenkins@tiscali.co.uk or look out for further updates in future Newsletters.

Lin Jenkins

Update: GP Training Day

We did it!

Dr Faraz Jeddi from RBH chaired the day and with 58 GPs and Health and Social Care Professionals attending, Drs Martin Turner and Chris Davies ably supported by Jenny Rolfe from the Oxford Care Centre, Jo Fitchett and Carol Allen from the Royal Berkshire Hospital and Netta Thorne, a former carer, provided an informative and encouraging programme to increase knowledge of MND and other rarer neurological conditions.

With an excellent lunch to start, the feedback was very encouraging to the branch - we had never done anything like this before and had been advised that it was unlikely that GPs would 'bother to attend'. But they did!

As a result of the event in October,

a) one of our team was invited to speak to the Long Term Physical Disabilities Team in West Berkshire to help their understanding of how they can improve their service to people with deteriorating neurological conditions,
b) a successful application has been made for funding for a Cough Assist machine for the RBH.

To the funders (Berkshire West Clinical Commissioning Group through their Partnership Development Fund), to all our speakers and to the Branch Committee - thank you for such an inspiring day.

Margaret Moss



Delegates at the GP Study Day



Speakers at the GP Study Day, (L to R Dr Martin Turner, Netta Thorne, Margaret Moss, Jenny Rolfe, Carol Allen, Dr Faraz Jeddi, Jo Fitchett)

Tales from our fundraiser, Lin Jenkins

I attended the Wokingham Mayor's Market on the Friday as I was too late to book for the Saturday. Although it was quite a wet day rather a lot of people dropped in, and my new "Washing Line Game" went very well. Didn't perhaps make as much money as a Tombola might have, but people WILL go home remembering the MND Association stall, which is just about as important. Several people took photographs of the stall, and hope to copy the idea themselves, so it will soon lose it's novelty value.

I was at the Reading Mayor's Market on Wednesday 11th December, and Yattendon Christmas Fayre on Saturday 30th November. I took a small Washing Line Game to each, together with a number of Christmas and Craft items to sell.

Car Boot Sales are a bit troublesome during the winter months. The forecast for Saturday 9th November was 'a slight chance of showers', so I loaded up the night before, and set off early on Saturday morning. No sooner had I got all my wares out on display, when the skies opened and it rained for the next 3 hours. Luckily the event was an indoor/outdoor event, so quite of lot of people still attended. The scout group loaned me a gazebo, which kept most of the rain out, so I continued with my day. Surprisingly I did make a small profit. I left everything in the car and ventured out again the next day. Woodley Shopping Centre is an ideal place for a Car Boot Sale. Although I had to pay £10 for my stall, there were a lot of people around, and I made quite a nice little profit. It was Remembrance Sunday, and it was lovely to share the 11.00am silence with so many people. It was a lovely sunny, but cold day, and I thoroughly enjoyed myself. As I write this I intend to do the same again this weekend - will see what the weather brings though!

Lin Jenkins

Paddy's bake-off

Volunteer Paddy Lunn has the perfect recipe for swelling the Association's funds.

For the second year running her tasty treats have piled on the pounds at a popular cake and cards sale.

Paddy's latest effort produced £466 with a little help from friends and family visiting the sale at her Sonning Common home.

Once again the sale featured a selection of cards with scenes painted by her late husband Rodney Lunn, a talented artist, who scooped a national award for his colourful work days after losing his battle with MND.

Paddy has recently printed a new batch of cards with views of Henley and London which she is selling in aid of the MND Association's Reading and West Berkshire branch.

Jane Gilbert



Paddy with her grandchildren Jack and Ella Wright who helped at the sale



Paddy, centre, with daughters Sara Wright and Joanne Lawson

CARERS' SUPPORT

Please be aware that the Carers' Grant for this year, expires at the end of March and so any claims must be made before 31st March 2014. Any carer of a person living with MND is entitled to up to £300 to spend on something that would make a difference to him or her. Payment is made on receipts, so any claims should be sent to the Treasurer, Ed Gryglaszewski, whose address is:

27, Ashton Road, Wokingham, Berks. RG41 1HL

Please discuss any possible projects with your Visitor or contact Joanna Knott (0118 984 4495).

Joanna Knott

WHEELCHAIRS AND SERVICING

You will remember from a previous Newsletter that Alec Jenkins gave a vivid account of his trials and tribulations with his wheelchair repairer, which included misinformation, lack of communication and generally poor service. Happily, this situation has now resolved, but not before we had taken up the case (and that of another person living with MND) with the head of the Wheelchair Service at RBH, Moyra Pugh.

She investigated the matter, took all necessary actions and then asked us to inform all MND wheelchair users what to do if problems occur in the future.

In the first instance, you should always go to the recommended wheelchair repair service company. If unreasonable delays occur or contact cannot be made to discuss the problems and all reasonable attempts to get satisfaction fail, then you are invited to contact Moyra Pugh directly. However you must give the Service Company the time and opportunity to deal with your problem before resorting to contacting Moyra Pugh. Her contact details for help if all else fails are: Moyra.Pugh@royalberkshire.nhs.uk or Tel No: 0118 322 5215

She has just put out a statement for all Wheelchair users:

'The Approved repairer contract for NHS wheelchairs in Berkshire West has now been transferred to Millbrooks. They can be contacted on: 08700 601471 or 01442 240541. Obviously this will be a very busy handover period for the wheelchair clinic staff with a great deal of extra work and we would appreciate your support and tolerance during this time.'

Joanna Knott

Meet Santa's little helper



Our Santa Alec Jenkins has just turned 70 and decided to take on an apprentice.

Meet his grandson Joseph who will be one in March and would rather be a Royal Marine commando judging by his crawling technique, says Alec from Newbury.

Those of you who went to the branch's Christmas Tea Party at Swallowfield Village Hall will recognise our regular gentleman in red who handed out hyacinth and panetonne gifts to people living with MND. Volunteers from the branch also served up some tasty treats for a festive tea.

Jane Gilbert

BENEFIT ENQUIRIES

We are aware that the Government's general Benefit Enquiry Line (BEL) has closed. Those seeking information or support on benefits are now advised to contact new helpline numbers for each individual benefit, or visit www.gov.uk
Full details are available on the MNDA website: www.mndassociation.org/benefits

NEW WHEELCHAIR PROTOTYPES UNVEILED

The MND Association is working with manufacturers to develop wheelchairs better suited to the requirements of people living with motor neurone disease and other neurological conditions.

The Association hosted an interactive workshop day in London where major manufacturers had feedback from people living with MND, occupational therapists, service managers, engineers and physiotherapists.

The project has been funded by a grant from the Department of Health and the new chairs, which should be available from statutory services, will better adapt to the often rapidly changing needs of people with MND.

Project Manager Pauline Matheson said: "The *Association was awarded a Department of Health grant last year to extend and continue our wheelchair service, currently provided from our Oxford MND Care Centre, to two further sites in London and Leeds and we also have been working to develop a specialist* 'neurochair'.

"Three manufacturers attended the workshop day and were able to get specific feedback on their latest prototypes from the people that both use and repair the chairs. It was a great opportunity to get everyone together to discuss how small changes to existing designs could make a huge difference day to day for people living with MND and all those who care for them.

"The project has benefited from the expertise and collaboration of so many people including Jenny Rolfe, our specialist MND Occupational Therapist who is based at our Oxford MND Care Centre and helped draw up the original specifications for these chairs of the future."

Liam Dwyer, who was one of the people living with MND at the workshop, said: "I have done more than 6000 hours in my wheelchair in the past three years so I know that parts go wrong. Some of my questions might have surprised the manufacturers but I did get some interesting answers. It was a great event overall and patient input now is vital to get it right for those who will get the devastating diagnosis of MND in the future."

If you would like to receive newsletters by email please contact Val Pearson: Valerie.a.pearson@btinternet.com

What's On?

Drop Ins

Wednesday 26 February at St Luke's Church Hall, Englefield Road, Theale, Reading, RG7 5AS from 12.30 to 3.00pm

Friday 25 April at Clewer Youth and Community Centre, Parsonage Lane, Windsor SL4 5EW from 1.00 to 3.00pm.



We would be very pleased to see anyone at these drop-ins and will even bribe you with sandwiches and cake.

Do come along and have a chat and a cuppa.

Quiz night

Saturday 12 April

After our successful event last time, do come to Englefield Social Club, The Street, Englefield , Reading, RG7 5ES starting at 8.00pm (and following the AGM) for a fun night!

Tickets available from Val Pearson (Phone 0118 9789063 or valerie.a.pearson@btinternet.com); £10 per ticket to include a ploughman's, dessert and nibbles and generous prizes for the winning team!

Come in a team or on your own - look forward to seeing you there!

Drinks available from the bar.

Carers' Support Meetings

Carers' Support Meetings are continuing bi-monthly, the last one being in Wokingham with a speaker from Wokingham Crossroads. The next meeting will be on **Monday 31 March** at 2.30pm at the Sue Ryder Hospice in Nettlebed . Hopefully the May meeting will be at Duchess of Kent House, Liebenrood Road, Tilehurst but details are still to be confirmed.

'THE NEWS'

from the MND Association ONLINE

This publication is very useful and informative. You can view the latest edition and archived electronic copies of The News at www.mndassociation.org/thenews

Why not walk to raise money for the MND Association?

The annual Walbury Hill Walk, organised by Newbury Rotary Club, takes place on **Sunday 11 May**, starting anytime between 11.00am and 12.30pm at Inkpen Village Hall, Upper Green, RG17 9QH.

You follow a fully signed and marshalled 5 or 8 mile route passing close to the summit of Walbury Hill, the highest point in SE England and returning to Inkpen Village Hall.

A donation of £1 per participant is requested to go towards the Rotary running costs. Any excess will go towards charities supported by Newbury Rotary Club (e.g. End Polio Now, Parkinson' UK, Stroke Association, Kids Out). Parrticipants must obtain their own sponsorship but if you do not have sponsorship you are very welcome to come and enjoy the walk and to give a donation towards the Rotary charities.

Further details can be found on the website www.newburyrotary.org, or by email to walk@newburyrotary.org or phone 01635 42027.

If you are interested it would help greatly if you emailed or telephoned to let the organisers know.

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