



Daredevil Keith Hood and Scruffy raised £2000 for Branch funds

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Charity Coffers defy Credit Crunch

Credit-crunch defying cash windfalls of more than £6000 have been pouring in from unexpected sources to help fight Motor Neurone Disease.

Donations from groups ranging from a dancing club to an international energy company will ensure a healthy start to the charity's new financial year.

All the donors have one thing in common – they know of the devastating effects of MND.

Their generosity means that the branch can improve the quality of life of people living with the disease and help to create a world free of MND.

Snow Go!

Have you been complaining about the snow recently? How about snow - Canadian style?

In the last year we have provided in Berkshire specialist equipment, not otherwise available, exactly when it is needed - people living with MND do not have time to wait.

Your vital funds have helped towards the cost of a stair lift, two wet rooms and ground floor alterations, transport, a massage table, therapy treatments, medical equipment, training for professionals and research projects.

At the end of each year fifty per cent of branch funds is given to the MND Association to help with its work in providing care and support in England and Wales.

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Specialist Nurse, Carol Allen, emailed us these pictures of her friend's garden in Canada recently - apparently the snow drift is 6 feet high - and the deer are wondering what all the fuss is about!
Thank you Carol.

HAL takes us forward—a step at a time...

A team from Cyberdyne in Tokyo has developed a computerised robotic suit which could be a revelation for elderly, semi-paralysed or disabled people.



HAL (short for "hybrid assistive limb") is a robotic "suit", which, the Japanese designers claim, can help people to walk.

After 16 years of development, HAL is now in production and available for hire in Japan for 225,000 Yen (approx £1,500) per month.

The design uses the natural electrical signals from the user's brain to anticipate movement, which are then picked up by sensors attached to the skin and transmitted via a battery-operated computerised unit to powered robotic braces strapped to the user's legs.

"We are ready to present this to the world," said Yoshiyuki Sankai, a University of Tsukuba professor

(and Chief Executive of Cyberdyne) who designed HAL.

Mr Sankai's invention first hit the headlines in 2006 when a Japanese man narrowly failed in his attempt to carry his quadriplegic friend on his back up a 13,741 foot peak in the Swiss Alps, using the suit. (see picture below).

Cyberdyne has already announced that 500 HAL robot suits will be leased to assist paralyzed patients at hospitals and rehabilitation centres in Japan. And, according to Mr Sankai, several European nations, have expressed interest in trying the suit.

A 'whole body' version of the suit is also in development.

"We are looking at the future use of the robot suits at construction sites, where workers have to carry heavy materials," , says Mr Sankai, "I believe technology becomes useful only when it works for people...I refuse any possible military use of my robot suits."

If you wish to see the suit in action, or find out more, visit,

uk.youtube.com/watch?v=ynL8BCXih8U or www.cyberdyne.jp/English/publicity/index.html

The University of California, Berkeley, and other researchers around the world are also working on similar robotic suits that increase mobility.

It is not known how useful HAL could be to plwMND, as the HAL suit relies on signals from motor neurons and it would depend whether sufficient electrical signals are still being produced to activate the computer,

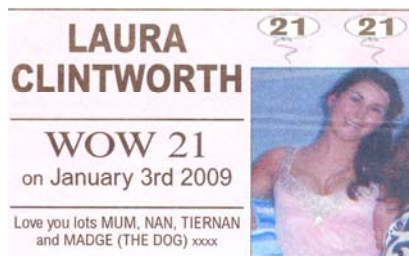
Colin Moss



Congratulations Laura!

Birthday girl Laura Clintworth, from Thatcham, got a surprise when mum Nicki placed this 21st greeting in her local newspaper.

Not to be outdone, the News-letter is happy to spread the word and sends many



congratulations to Laura, one of the branch's fabulous fundraisers.

Jane Gilbert

Wokingham Street Collection raises £760

Congratulations to Jan Gryglaszewska and her team, who rattled the tin on a cold and wet day in Wokingham recently to raise £760.

A huge "thank you" to all the 15 strong team, including committee members, Jan's friends Brian, Becca and Mandy Trowbridge and new volunteers, Liz Cheney, Sue Hand and Sue Price.

Credit Crunch?

Where the money is coming from

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International energy company, the BG Group, has donated £2,000 to help people in Berkshire living with the debilitating condition.



A world leader in natural gas with operations in 27 countries it has its HQ at Thames Valley Park, Reading, where it employs 1500 people.

Helen Lowson, the firm's government and public affairs co-ordinator, is one of an eight-strong community investment team which looks at local needs and chose the Association to benefit from a big charity cash share-out.

She said: "I am really pleased we were able to help out."

The daring adventures of a little bear called Scruffy and his dare-devil pensioner friend Keith Hood have raised £2,000 for branch funds.

Keith, 68, took the teddy with him when he did his second parachute jump for the MND Association last summer. The cash was part of a total of £6,000 raised to help fight MND during his year as a Grand Primo of the Royal Antediluvian Order of Buffaloes in Norfolk where he now lives with his wife Fay and her bear Scruffy.

The couple, formerly of

Pangbourne, devoted their fund-raising to two friends who died from MND – John Nichols from Sheringham and Graham Hodgetts of Thatcham.

Graham's widow Maureen visited them recently and was bowled over when they presented her with a cheque for £2,000.

She explained: "I was so shocked because I didn't know they were going to do the presentation. It was very emotional."

Fay and Keith had both worked tirelessly, she said, organising an auction, and garden party as well as lucky dips, coffee mornings and more extreme adventures in the air.

Molly and Alan Denton are to give £1,000 from funds raised at their dancing and social club in Tilehurst.

Every year the Over 40s club gives £3,000 to local charities. They raise cash at regular dances at the 79th Scout Hut in Armour Road and take a team of sequined dancers to entertain at old people's homes.

Alan, aged 75, worked many years ago with a man who had MND and it left a lasting impression on him.

Molly, who is 71, said: "My husband was devastated about it."

The couple, who are both very active, say some of their members are in their 90s and they still come dancing.

Marie Taylor chose the MND association to benefit from her two years as ladies' captain at Bearwood Golf Club in Sindlesham.

She said: "We are a relatively small club but I am delighted to say that we have already collected well over £1,000 with more still to come."

Marie chose the charity because her footballing grandfather died from MND when she was a young girl and she also lost a tennis and golf playing friend to the disease more recently. "A surprising number of people seem to know someone who has succumbed to it," she said.

The lady golfers raised the money with bring and buy sales, raffles, captain's drive-ins where people guess how far the ball has been hit, a sale of photographs from events and donations.

Marie will present the cheque when she finishes as captain at the Bearwood Ladies' annual meeting on Monday March 23rd.

Jane Gilbert

Sarah's Story - The Shocking Reality of MND Diagnosis

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A hard-hitting film is spear-heading a brand new campaign to help raise greater awareness of Motor Neurone Disease.



Sarah's Story follows on from John's Journey and features a 90-second film clip that packs a powerful punch.

The film, currently being shown at over 50 independent UK cinemas, tells the story of a young woman who is suddenly "attacked" by MND.

It shows the psychological and emotional impact of getting a diagnosis of MND and the different stages of the body's deterioration as the disease progresses.

The film features Sarah Ezekiel, who is living with the disease, and after whom the campaign has been named.

An actress plays the part of Sarah and as her body deteriorates, showing the muscle-wasting effects of MND, the actress's head is superimposed on the body of Sarah Ezekiel.

This is the first time the MND Association has produced a broadcast advert to raise awareness of the disease which has relatively low recognition among the general public.

Its hard-hitting style is likely to shock some audiences but the aim is to stimulate viewers' curiosity to find out how they can help the charity fight back against MND.

Donna Cresswell, director of Communications at the MND Association, explained: "With Sarah's Story we didn't set out to shock.

"The bottom line is that the progression of MND is shocking and we are bringing this truth in front of people who have little or no knowledge of this dreadful disease."

As some members may find it distressing to watch, branches are being consulted about the best way to communicate

about it within the Association.

Chair Margaret Moss, publicity officer Jane Gilbert, and committee member Colin Moss, who is living with MND, joined a viewing panel in Banbury to watch the film before its general release.

Jane said: "I was surprised to learn that surveys have shown that spontaneous awareness of MND is less than one per cent. When people are prompted awareness goes up to fifty per cent.

"Hopefully this powerful film will make a big difference."

The film, certificate 15, has been created at virtually no cost to the Association, with free support within the advertising and film industries.

At the time of going to press no local cinemas were screening the film.

Watch the film and a film on the making of Sarah's Story at www.sarahsstory.org.uk



Jane Gilbert

Have you had a flu jab?

The Department of Health advises that people living with chronic diseases, including Motor Neurone Disease (MND)

should get the flu jab if it has not already been offered to them. People living with MND are seen as an 'at-risk' group who should have the vaccination this winter.

For more advice about getting your flu jab, contact MND Connect on 0845 62 62 62 or email MND Connect at mndconnect@mndassociation.org

The News

Polo Player's Fight to Cure MND

Professional polo player David Heaton-Ellis has become the third person in his family to be struck down by Motor Neurone Disease. Once this is achieved drugs can be screened that can, they say, arrest and even reverse motor neurone degeneration.

Last year after having problems playing in Argentina he was diagnosed with the same disease that killed his racehorse trainer brother, Mikie, aged 42. Their loving aunt Cairnie had also been a victim at the age of 55. The Heaton-Ellis Trust aims to raise £1 million to buy a new generation DNA sequencing machine for the neurological research team at King's College Hospital led by Professor Chris Shaw and to run it for the next three years.

David, who is now in a wheelchair, fears his nineteen month old son has a fifty per cent chance of getting the familial type of MND and he is battling "to extinguish this cruel disease now."

He and his young wife Sophie, from Headley, near Newbury, have set up The Heaton-Ellis Trust with a group of friends and supporters. Their goal is to discover all those genes responsible for causing MND.

*It must be stressed that this appeal is being run independently of the MND Association and any support must come from individuals rather than the branch to comply with the Charity Commission regulations.

You can watch a film, made for the appeal, of David and his family on Youtube at:

<http://uk.youtube.com/watch?v=08Qg93xKrl4>



Lady Halifax went along to the recent the launch in London and added,

"There must have been over one hundred friends and supporters there to watch the moving film of David in his wheel chair in his garden with Sophie and Georgie, sitting on his knee, smiling and waving. Lets hope this new machine will help protect Georgie from becoming the 3rd generation to inherit the Motor Neurone Disease gene and also help many others of his generation." *Jane Gilbert*

Walks for Charity

Rotary Club of Newbury



We invite you to participate in our **Annual Sponsored Walk** (4 or 8 miles)

On Sunday 10th May 2009

Starting times: 12.00 – 13.00 hours (latest) at Snelsmore Common
For sponsorship forms, email: cbartlam@mixingsolutions.com

Duchess of Kent House Charity in conjunction with Motor Neurone Disease Association

Englefield Charity Fun Walk

Englefield Estate, Englefield, nr. Theale RG7 5EN
2 p.m. Sunday, 10 May 2009

Join Duchess of Kent House (Hospice) Charity & MNDAs on this beautiful gentle 3 mile walk including farmland, the gardens, deer park and lakeside.

Please pre-book:

Duchess of Kent House walkers:
www.dokhc.org.uk

0118 939 4889
sue.day@dokhc.org.uk

MNDAs walkers:
www.mndrdgwberks.freeuk.com

0118 978 9063
valerie.a.pearson@btinternet.com

It's "Snow Go" for Dave too

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Runner Dave Napper, from Finchampstead, had planned to run in the Wokingham Half Marathon on February 8th, but was scuppered by the snow.

Some of you will remember Dave when he headed up the dolls and bears stall at the Englefield House garden open day in the Summer.

Now Dave's energies have been put into running to raise funds in memory of his mother-in-law Beryl Chard, from Reading, who died from MND in June.

He said: "Her illness was made a bit more tolerable though by the love,

care and support of the Reading and West Berkshire MND Branch. This has forced me out of retirement and made me get the trainers on again!"

As the Newsletter went to press Dave was waiting for a date for the re-scheduled Wokingham run and plans to transfer his pledges to either that or the Reading half marathon on March 29.

If you would like to sponsor Dave he has set up a fundraising page on the internet at:

<http://www.justgiving.com/davenapper>

Jane Gilbert



A six-strong team of mad-cap cyclists are planning to cycle from Casablanca to London in September to help fight Motor Neurone Disease.

One of them, 20-year-old Jack Gilbert, from Bucklebury, is the son of our publicity officer and took up the challenge in memory of his grand-mother who died from MND.

Jack, a second year engineering science student at Balliol College, Oxford, and his friend Chris Kroon, who is reading biomedical science at

Imperial College, London, are using the internet networking site Face book to help raise vital awareness as well as funds.

The pair have teamed up with Chris's mum Annelie Green and her husband David from Kintbury, his brother Steve Green and friend Richard Liversidge, a seasoned triathlete.

Sahaj Sethi, from Compton - a King's College, London, medical student friend of Jack and Chris - has agreed to be their support crew

They have planned their own route - 1,000 miles in 100 hours- and are paying all their expenses so that every penny raised will go to the

MND Association to help with research projects.

Jack's mother, Jane Gilbert, is delighted the team has chosen the charity to benefit from the challenge and will be seeing them off in Morocco.

She said: "I draw the line at cycling but I'm helping with a few fun events beforehand like night golf, using glow in the dark balls, and a Midsummer Madness Party to help boost their sponsorship money".

If you would like to support their quest for 1000 miles in 100 hours log onto <http://www.justgiving.com/casablanca2london>

Jane Gilbert

Thank –You Lunch Rescheduled

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The Thank You Lunch has been re-scheduled for Sunday 15 March.



Due to the recent heavy snowfall and icy conditions, the popular

Thank You Lunch was called off just the day before it was due to have taken place. Five of the organisers came to the decision shortly after meeting at the Ufton Court Tithe Barn venue on Saturday 7th February.

In the interests of safety it was

deemed that the car park, footpaths and access roads were too dangerous for everyone. With no rise in temperatures forecast, Margaret, Val, Jane, Joanna and Wendy contacted everyone who had accepted to prevent anyone making unnecessary journeys, and Margaret was at the Tithe Barn on Sunday morning – just in case anyone arrived.

The lunch is held every two years, by invitation, as a way of thanking our hard-working volunteers and supporters who have helped to raise funds and promote our cause. The guest list also

includes people living with the disease and their carers, professional staff who give dedicated care to PLwMND, the press, and civic dignitaries.

Fortunately both Ufton Court and the caterer are available on Sunday 15 March so we hope that everyone can attend on the new date.

Invitations will be going out again shortly but, even if you have indicated you will come, it would be really helpful if you would reply when you have the invitation. *Colin Moss*

£15,000 raised for Jumbulance Holidays

The recent Awareness Raising Event for Jumbulance raised a total of £15,000 towards this excellent charity, which organises holidays and



short breaks especially for the disabled. Carers can accompany or Jumbulance can organise

a carer if you wish. The holidays are organised by Chris Chisholm (née Cook), formerly of the Duchess of Kent House, and this year group holidays are planned to the Brandenburg Lakes and Berlin in June and then a week as part of the Findhorn Community in Scotland in September.

A third holiday is planned in Southern Brittany from the 4th to 9th October in a

brand new Jumbulance, fitted out with a disabled toilet, kitchen area, air conditioning, five beds and places for manual and electrical manual wheelchairs.

For more information on Jumbulance or any of the holidays planned, contact Chris Chisholm at cookchris@aol.com

Anne Hallifax





You've got mail!

Naidex is the UK's largest event for homecare, disability and rehabilitation, and a visit is recommended by Roland Lewis, who says,

"We were amazed at the number of exhibitors showing beds, motorised wheelchairs/scooters and stair/through lifts. Naidex gave us plenty of ideas and was well worth the visit."



For Sale

Please see attached a photo of my dad's scooter which we are trying to sell.

It is a Shoprider mobility 3 wheeler scooter. Brand new charger recently bought worth £102. Scooter is approx 5yrs old. Solid tyres. £300 or nearest offer.

Carol Barnett, mobile no. 07766 987 687

Diary Dates

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Drop-in Meetings

The Mansion House Prospect Park Reading	Wed 4 Mar 6.30-9pm
Tyndale Baptist Church, off Shinfield Road, Reading	Thurs 16 Apr 12-3pm

Thank-You Lunch

Tithe Barn, Ufton Court	Sun 15 Mar 12.00
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Marathons

Bath	15 Mar
Reading	29 Mar
Wokingham	TBA
London	26 Apr

Spring Conferences

Leeds	5/19 April
Taunton	10/17 May

Charity Walks

Newbury Rotary Club Snelsmore Common	Sun 10 May 1pm
Englefield House Walk	Sun 10 May 2pm

Please see insert for contact details and if you wish to take part in a team walk at either of these venues.

MND link to Football?

A friend drew my attention to this article in The Times recently:

A spate of deaths from motor neurone disease has rocked the game in Italy.

The latest to be stricken is Stefano Borgonovo, a 44-year-old former striker for AC Milan. His announcement that he was suffering from motor neurone disease (MND) was made from a wheelchair with a computer-generated voice and has chilled a nation of football fans.



And in a separate link, a senior doctor urged the English Football Association to investigate whether the sport contributes

to motor neurone disease (MND)

Andrin Cooper, a spokesman for the FA, said it had no plans to conduct a "specific MND study" at present. However, he added that the organisation was involved in a 10-year study on how "heading the ball affects the brain" and that its medical committee would be meeting next year to assess the preliminary results.

If you wish to read the full article, follow the link below:

www.timesonline.co.uk/tol/sport/football/european-football/article5114400.ece

Colin Moss

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	Chair Margaret Moss 0118 9470871	RCDA Fiona Turner 08453 751854	Treasurer Ed Gryglaszewski 0118 9789069	Publicity Jane Gilbert 0118 9714172