



South & East Somerset Newsletter

Chairperson's Report

Following another successful AGM, the Branch Committee duly was elected. A few changes have taken place. Meg Longman has stood down from her role as Chairperson and we would like to take this opportunity to thank her for all her hard work and input into the Branch it has certainly been appreciated.

I, Margaret Small have agreed to stand as Chairperson, John Hayward as Vice Chair along with his role as Secretary. Wendy Knudson was nominated to work alongside Edward Thring in his role as Treasurer at the next AGM, as Edward wishes to retire after 30 years of devoted service to MND Association.

I feel privileged to take on the Chairperson role having been in the South and East Somerset Branch for over 16 years, in fact from the commencement of this local branch, and having enjoyed working with a great team of people, developing the branch to be supportive to so many amazing people living with MND, carers and their families, and Health and Social care Professionals.

I have a great understanding of MND as my background was one of a Specialist Nurse in the NHS community working with people with Neurological conditions until my retirement 3 years ago. Although a small branch, we experience challenging times, but with grateful thanks over the past year to the Mayor's fund and legacies the branch remains in fairly good financial position and have therefore been able to help improve quality of life and maintain people's dignity during their illness. The branch I know will continue to be motivated in achieving a good support network for people with MND in the forthcoming year due to the passion and commitment of all who serve.

Warmest regards, Margaret Small

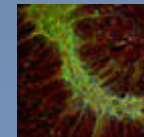
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TREAT FOR CRICKET FANS

Top class England and international cricketers, past and present are uniting to raise funds for research into MND, after the wife of former international Chris Broad was diagnosed with the condition.

The side-a-side charity tournament will see international cricketers playing in the teams and joining guests in the VIP marquee for lunch, where the winners will be presented their prize by Chris's son, England fast bowler Stuart Broad.

This event is a great opportunity to raise awareness and funds for the MND association, while watching cricketing legends in action and having a great day out.

The tournament takes place at Wellesbourne Cricket Club, Loxley Close, Warwickshire on Sunday, 18 July from noon. Tickets are £20 for adults, children 16 and under £15, under twos free. Family of 2 adults and 2 children £50

Contact Hannah.Male@sectormarketing.co.uk at Sector Marketing or call 01275 335 911.

When Insults had Class

The exchange between Churchill and lady Astor:She said,
“if you were my husband I’d give you poison.”
He said, “if you were my wife, I’d drink it.”

A member of Parliament to Disraeli:

“Sir, you will either die on the gallows or of some
unspeakable disease”

Disraeli “ that depends, Sir, whether I embrace your
policies or your mistress.”

“He has all the virtues I dislike and none of the vices I
admire. “ (Churchill)

“ I have never killed a man, but I have read many
obituaries with great pleasure.” Clarence Darrow.

“ I am enclosing 2 tickets to the first night of my new play;
bring a friend....if you have one.” George Bernard Shaw
to Winston Churchill.

“Cannot possibly attend first night, will attend second....if
there is one”.

“He has no enemies, but is intensely disliked by his friends” Oscar Wilde.

“He is a self-made man and worships his creator.” John Bright.

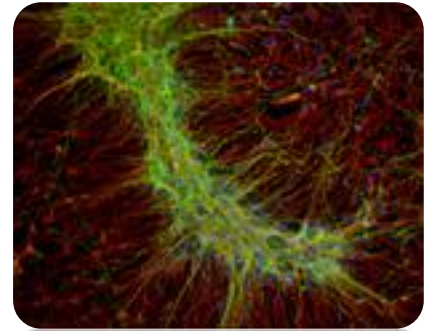
I didn’t attend the funeral, but I sent a nice letter saying I approved” Mark Twain



RESEARCH

This summer the Association will begin funding its first stem cell research programme. The programme will involve induce pluripotential stem cells (iPS), which are created by reprogramming adult skin cells so they behave in a similar way to embryonic stem cells. The iPS cells can then be used to generate living human motor neurons for laboratory study and, eventually, for efficient drug screening.

You can read all about the programme on at:



http://www.mndassociation.org/research/research_explained/stem_cells_and_mnd/index.html.

AND MORE

Chicago researchers have found clumps of the 'FUS' proteins in motor neurons of people with familial MND and in motor neurons of people with sporadic MND.

Dr Brian Dickie, or director of research development says that, " This adds weight to the opinion of many scientists that we may at last be holding some of the key pivotal process that are occurring in MND".

You can read more at



http://www.mndassociation.org/research/news_in_research/fus_clumps_found_in.html.



LEVELING OUT

The owner of a family home in Somerset is offering her home, free of charge, to people with MND and their families for short breaks in the summer of 2010.

The aim is to provide an opportunity for rest and relaxation in a peaceful countryside environment.

The house is in the village of Crickham, near Wedmore on the Somerset Levels. It is 4 miles from Cheddar Gorge, and within easy reach of Wells. It has wonderful views across Somerset countryside. There is a field at the front, and a newly planted wood 200m away. The house is spacious and detached. It can comfortably accommodate up to 8 adults and a small child.

Downstairs

Master bedroom with en-suite and level access onto decking outside.

Double bedroom with shower room and toilet and rear access to the house for wheel chair user.

Large kitchen/breakfast room.

Large sitting room.

Separate dining room.

Utility room.

Upstairs

A double bedroom with small gable room suitable for cot or bed for small child.

A large bedroom with a single bed and plenty of space for a campbed or mattress on the floor. Shower room with toilet.

Outside

A large deck area with ramp allowing wheelchair access to the house via the French windows in the master bedroom.

A hot tub at one end of the deck.

A large garden, field and newly planted wood to the front of the house.

A local coordinator will:

Greet guests on arrival and show them round

Ensure the house is cleaned when guests leave.

Stock the fridge with basic foodstuffs, and stock the freezer with locally sourced ready meals if guests would like this (at no costs). Ensure that any equipment that needs to be provided for guests is in place before they arrive.

Give information about local facilities to families staying there.

Deal with any unexpected situations/emergencies relating to the house or garden.

Bed linen will be provided for all beds. Any children sleeping on the floor will need sleeping bags pillows and airbed.

There will be no costs to guests for using the house. Guests may apply to the MND Association for help with funding travel costs to and from the house.

The house will be allocated on a 'first-come, first-served' basis to families who meet the criteria. Expressions of interest can be made by telephone to MND Connect anytime after Tuesday 1 June 2010. **MND Connect - 08457 62 62 62**



2010 RAFFLE

The first MND Association-wide raffle last year raised nearly £135,000 for care support services and research projects, £18000 of which came from branches and groups.

Taking part in the raffle gives people the chance of winning one of 25 great prizes. As well as helping your local branch raise much needed funds you will be raising awareness.

I am enclosing raffle books with each newsletter. All ticket stubs and money to be sent back to me please – Lynda Clark, 11 Compton Road, Yeovil, BA21 5BZ. Tickets not sold please will you also return to me. Cheque's to be made out to South and East Somerset MNDA.

1st prize

Holiday of a lifetime or £4,000 cash.

2nd prize

Flat screen HD TV or £500 cash.

3rd prize

Pation furniture or £250 cash.

Runners up

22 Roberts Radios.



MND ASSOCIATION'S NEW CAMPAIGN

June sees the public launch of the new awareness campaign Incurable Optimism.

The campaign centres around a bid by father of 3, Patrick Joyce, who lives with MND, to create 100 portraits of fellow 'Incurable Optimists'. We also want people to join the campaign by sharing stories of their own optimism.

Patrick Joyce, 40, was diagnosed with MND in March 2008. He lives in Wells with his wife Kathy and three young children Reuben, Elliot and Nancy. Patrick says:

"I am a writer, an inventor, an artist and amateur neurologist. I am a husband and a father. I have motor neurone disease and I'm proud to be an incurable optimist: MND is incurable but so is my optimism. Before my diagnosis of MND I was an artist. Now the disease has affected my arms and hands and I am finding it harder to paint. I want to continue to show my talent for as long as possible and use both my talent and my story to help the Association create a movement of incurable optimism. This is why I've set a challenge to draw the portraits of 100 incurable optimists."

Patrick has already begun to work on his challenge and has produced 4 finished portraits: one of his wife Kathy, one of Dr Martin Turner, who many of you will know is a leading figure in MND research based in Oxford and Sarah Ezekial from last year's Sarah story campaign. Patrick speaks to each of his subjects in advance of starting work and incorporates their own words into the picture, as a message of optimism to all of us.

You will be able to keep up to date on Patrick's 100 portraits challenge at <http://www.patricktheoptimist.org>

Incurable optimism drives us. Mel Barry, communications manager, explains the thinking behind the campaign.

"We all know motor neurone disease is currently incurable. But so is our optimism. And this is

what drives the association to find a cure. The Association is made up of incurable optimists who are determined to beat this disease. It's also the driving force that keeps the scientists and clinicians that we fund conducting world leading research that will one day beat this disease. To turn incurable to curable, and to ensure people with MND get the best possible care and support, we need to raise awareness of the disease and the work of the Association. Staff will be focusing our PR and online activity on this campaign for the next few months.”

What you can do:

Talk a look at <http://patricktheoptimist.org/>.

Send Patrick a message of support at: http://patricktheoptimist.org/?page_id=21

Include the address of Patrick's website at the bottom of any personal emails you send – spread the word.

During awareness week we have once again secured advertising billboards across the national rail network and London underground stations. The adverts will highlight our incurable optimism and will feature Patrick. If you do spot any we would love it if you could take a photo of yourself in front of them and send it to Jennifer Saunders, at national office.

Patrick working



FUTURE MEETINGS

Our Committee meetings are held on Monday evenings alternate months at 7.15pm at Meg Longman's home. Unfortunately, we have not sorted out our dates after June 14, so anybody interested in attending please ring me, my number is on the back.

The support meetings run by Lynda Riley and myself are also held alternate months at the:

**Rocky Mountain Garden Centre
Masbury
Wells**

2.30pm – 4.00 pm

These support meetings are very successful, being attended by people with MND, carers and friends. Those attending swap their email addresses and phone numbers and support each other between meetings. We would love to see anyone involved with MND to come and join us.

The Committee

Patron	David Laws MP
The Chairperson	Magaret Small
Treasurer	Edward Thring
	Wendy Knudson
Vice Chair	Margaret Small
Secretary	John Hayward
Contact Person	Lynda Clark
	01935 424 364
Newsletter Contact	Lynda Clark
	11 Compton Road
	Yeovil, BA21 5BZ
Association Visitors	LyndaClark
	Lynda Riley

This is not an official MNDA document. Any comments or suggestions put forward are those of the editor and should be treated as such. Please refer to your medical practitioner for all Medical queries.