

Lots of Fund and Awareness Raising to end 2013

New Year's Day Party

The Lord Nelson, Broadstairs and WIRED hosted a Grand New Year's Day Party, on Wed 1st January at 3.30 pm.

There was a Monster Raffle, food throughout the party and lots of superb music. All proceeds from the event will be donated to Motor Neurone Disease



Association in East Kent.

A total of £660.36 was raised and this money will be used to support people living with MND and their carers.

Many thanks to Brian Langsdon on engineering, Frank Harvey as MC and organising musicians and to Ken Wards who organised the party.

Many thanks to Dianne, Dave, Fauzya and Mira the staff at The Lord Nelson.

Thanks to all the musicians who generously gave their time and finally thanks to the customers of the Lord Nelson for their generosity

Boxing Day Swim



Ben Terry pictured left, whose father has Motor Neurone Disease, helps care for his Dad at home along with his family. Ben makes videos on YouTube about his life, and the

ways that he helps his dad.

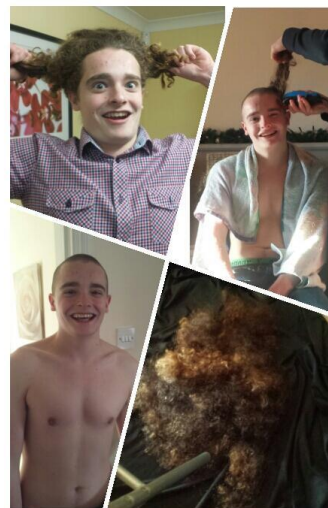
For some years now Ben has braved the cold sea on Boxing Day to raise funds for the Motor Neurone Disease Association.

On Boxing Day 2013, at the stroke of midday, Ben entered the sea at Dover after spending time working the beach as Spider Man together with friends raising money.

Ben was in the sea for well over 10 minutes and earned every penny of the £458.19 he raised, which far exceeded the £250 he had hoped to raise. If you would like to add more, please visit Ben's Just Giving Page at <http://www.justgiving.com/MNDA-EastKent3>.

Ben was ably supported by family and friends and the grand result of the day's activities now exceeds £600.

One of Ben's friends James Revell pictured right, decided to get his hair cut, first time in 10 years and raised an amazing £525, visit James [Just Giving](https://www.justgiving.com/james-revell/) Page at



<https://www.justgiving.com/james-revell/> if you want to add more.

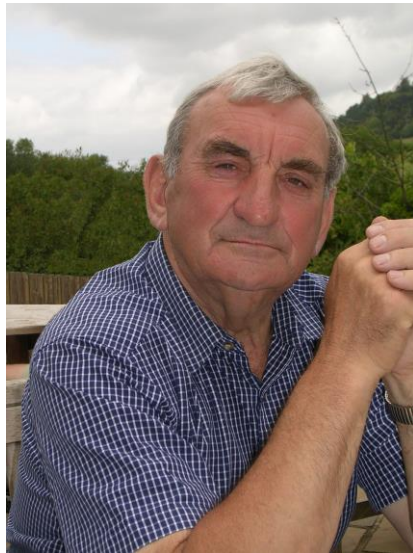
East Kent Branch of MND Association would like to thank Ben, James their families and friends for these most successful fund raising events.

Research Donation

A charitable fund set up following the death of Andrew (Andy) Keay in a road accident has donated £5,000 to MND Association for research.

The donation is in memory of Ian Keay pictured right, Andy's father, who died from MND in 2010. As both Ian's father and sister died from MND, research into finding a cure for this disease is paramount.

The charitable fund was set up by Francesca, Andy's fiancée, and any donations are agreed with Martin, Andy's brother, and Judy Keay who is the East Kent MND Association Visitor and a member of the East Kent MNDA Group committee.



Saltwood Boxing Day Run

Several hundred people packed the village green, as 750 runners, including Chrissie Batts and Hayley Cook, pictured right, braved the elements for the annual Saltwood run. They were rewarded with glorious sunshine, as they battled a very wet and muddy course around the Brockhill and Saltwood countryside. There were runners from many parts of the world, running in the event which has taken place for the last 39 years.



The event is held each year to raise funds for MND, in memory of founder runner Terry Davies who died of MND a decade ago and a substantial sum has been raised for MND in East Kent. This year's run raised £2000 from the race, £250 from local Rotarians and a collection of £90 from a collection on the day. Paul Stanton ran with friends in memory of his brother Mark and raised £1830, please visit <https://www.justgiving.com/Paul-Stanton5> if you would like to add more. We understand that

Paul's company has agreed to match any money he raises, making the current total £3660, a fabulous achievement.

Huge thanks to Greg Boarman and his team for their sterling job in organising this wonderful event. 2014 is the 40th anniversary and should prove to be even more popular.

Canterbury Ladies Choir

The annual Christmas concert by the Canterbury Ladies, Girls and Chamber Choirs was held at the Salvation Army Hall in Canterbury on Saturday 14 December. The after-concert collection raised £210 to support people living with MND in East Kent. This sum will be doubled as a French educationalist has offered to match fund anything the choirs raise over the Christmas period.

Christmas Fun Day

The Fun Day organised by Amanda Barker at Essentially Hops, Chalkpit Farm, Bekesbourne on Sunday 15th December was a success and raised money for the Pilgrims Hospice.

Amanda has recently lost a friend who had motor neurone disease and so she had a special carol collection on the day which raised £266.15p for MNDA funded researcher; Professor Ammar Al-Chalabis's project.

binElla Jazz and Champagne

This event was sadly cancelled due to the risk of flooding; a Burn's Night has now been arranged for Jan 24th. More details page 8.

I AM BREATHING

As part of the MNDA's national awareness raising campaign we held a showing of the BAFTA award winning documentary "I am Breathing" at Kent and Canterbury Hospital Postgraduate Centre, 10th December, 2013.

The film is about Neil Platt's experience; within a year, going from being a healthy 30-something British bloke with a great sense of humour to becoming completely paralysed from the neck down, thanks to the devastating illness he has inherited – known as MND.

As his body gets weaker, his perspective on life changes. His humour remains, but new wisdom emerges:

"It's amazing how adaptable we are when we have to be.



It's what separates us and

defines us as human beings."

Knowing he only has a few months left to live, and while he still has the ability to speak, Neil puts together a letter and memory box for his baby son Oscar and communicates his experience and thoughts about life in a blog – and in this film which he was determined to make.

The directness of his communication mingles with images of the sensory details of a life well lived, and makes us revalue the ordinary.

His blog posts form the film's narration as he tells his own story through memories and impressions of his life – the sheer joy of falling in love, of partying with his mates, of fast motorbike rides. Through his determination to share his final journey, he makes us ask questions about our own lives.

The audience was made up of healthcare professionals from East Kent, who gave up a couple of hours of their evening to view the film and a short introduction by Katy Styles. Refreshments were donated by The Park Inn, Ladywell, Dover.

As Campaign Co-ordinator for MND East Kent Development Group, Katy asked those attending to sign the MND Charter and to the talk to their colleagues about the key messages from the film. Katy said afterwards, "Showing the film, to healthcare professionals was one of the most rewarding things I've ever done. I am determined to show this film at more events next year."

A great deal of literature about MND was taken away and £25.00 was donated.

Witches, Wine and Wisdom

Thanks to all the Witches who took part in a quiz at The Park Inn public House Dover, on Thursday 31 October 2013. 5 teams entered and each created their team names.



Winners were "Best Dressed" – photo above; they also won the prize for best fancy dress.

Chrissie and Jim West (Below) were in the team called "Pussy Galore" and put up a great opposition vying for the lead with "Best Dressed" Max Johnson was Quiz Master and did a great job keeping all the teams in order.

A small raffle was held – Chrissie Batts won first prize £35 meal voucher courtesy of 'Brickfield' Table Table restaurant.

Thanks to all participants, funds were raised for the MND in East Kent.



Annual Conference

Annual Conference 7th September 2013 Stansted, it was attended by Mark & Katy Styles from the East Kent Group.

The key theme of the conference was future planning. After the official business of the MND in the morning, we were invited to take part in small workshops to identify priorities for the MND.

Mark and I were sent to different rooms with a facilitator and trustee to discuss the priorities we had for the MND. We quickly learnt that people's experiences of care throughout the country were totally different. Many people had access to a specialist MND Care Centre, while others did not. Most people agreed that along with care, campaigning was important, as well as research. Different groups put emphasis on different parts. All of the carers wanted more integrated care as there were too many appointments, on different days, with different specialists in different hospitals. In the afternoon, Professor Kevin Talbot, Consultant Neurologist at John Radcliffe Hospital, Oxford and Co-Director of the MND Care and Research Centre gave a talk about collaborating with families to gather evidence for his research. He gave a call to arms to everyone, to volunteer to take part in a Biomarker Study.

But perhaps the most important part of the day is when members can sit and chat and swap experiences. Knowing you are not on your own makes it all seem a little more bearable.

Dr Martin Turner's Biomarker Study

Everyone who was at this year's Annual MND Conference in September will have heard Professor Kevin Talbot's call to arms. He wanted volunteers to give up time to take part in biomarker studies. People with MND, people without MND, people with related disorders, hereditary MND patients. He wanted everyone. Following our visit to the Oxford MND Centre earlier on in the summer, we have volunteered to take part in Dr Martin Turner's biomarker study into motor neurone disease.

We are having two brain scans, a MEG scan and an MRI scan. As I am the same age as Mark, I am useful for the study, as a healthy volunteer. Anyone who knows me well will be laughing at this point....

The purpose of the biomarker study is to discover a test to speed up diagnosis of MND, to see how the disease spreads, and to monitor its activity. This may lead to more targeted drug treatments in the long term. Well here's hoping.

It was be great to be at the cutting edge of MND research and to be in Oxford. Mark and I spent the first afternoon in the MEG scanner.

Apparently there are only 8 of these in the UK. It was like an MRI scanner but instead of lying down in it you sit with the scanner coming down around your head. Like an old fashioned salon hair dryer you would have seen in the 50s.

You have electrodes taped to your arms, face and head. These record your eye movements and finger movements. You are asked to follow an arrow on the screen, if it points left you lift your left index finger, up and down on a LED control pad, but only if the next light is green. If red you don't move. Not as easy as it sounds I can assure you. This was looking at changes in your brain in response to thinking and action.

The second day was time in the MRI scanner. I had an extra test with a different coil and helmet. This was to measure different chemical changes in the brain, over the whole brain. If you are even slightly claustrophobic this isn't a test for you as you have to spend time in the scanner continuously.

Below is a link to Dr Martin Turners BioMOX project which is the study we took part in.

<http://www.mndassociation.org/2866b9aea41d410db99db945e625fbd2?site=283fc445-39c4-4d60-8bbc-3bd9e5e54ec1>

Mark is a book for a day

Mark Styles took part in his work's Disability Awareness Day at his office on 4th December. Mark was a living book: people could read his synopsis, about his specialist subject, "living with MND". They could then book him out, like a library book, where he gave talks for 20 minutes at a time.



Mark pictured left, said, "This is an innovative way of raising awareness amongst colleagues of a variety of disabilities. It was very enjoyable.

Mark also combined his talks with a film showing of "I Am Breathing".

Music Download

Download this great recording for a donation to MNDA.

The recording is released on the Cath'n'Dad label, which works on the principle of making recordings available for download. Donations of whatever you feel suitable are then donated to a charity of the Artists choice.

In the case of this record, Cara has nominated MNDA, so a part of any donation you make will be paid directly to MNDA.

To download the album, please follow this link

<http://cathndadrecords.bandcamp.com/album/im-still-standing>



Swarling Manor Walk



Sunday 23rd Feb. 11 am.

Take a stroll through our beautiful grounds to catch a glimpse of the stunning snowdrops that flourish for a few weeks every year.

After you've taken in the surroundings make your way to our barn to buy some lovely homemade cakes and sit for a while with a cup of tea or coffee.

We have some brilliant prizes in

our raffle so be sure to buy a ticket or two on the day.

Entry to the grounds, £4 for adults and £2 for children.

We regret that dogs are not permitted due to livestock in the area. Call 01227 700377 or visit

<http://www.swarlingmanor.com> for more

information about the event.

National News

Football v MND

OUR new Football v MND awareness campaign is off to a fantastic start, with four clubs getting involved in its opening week.

Former professional footballer, Mark Maddox played over 300 times for Altrincham FC before he was diagnosed with MND in 2010.

Having run the London Marathon and skydived for the Association, he is now on a mission to raise awareness of MND even further.

Mark said: "I want to reach those people I can't tell personally. By running our special awareness poster in match day programmes up and down the country, both Football League and nonleague teams can support the Association, and branches and groups can reach a new audience too."

Mark's former club Altrincham FC were the first to take part during their Conference North game



Altrincham FC Chairman Grahame Rowley, granddaughter Daisy and Rocky Robin.

against Guiseley FC on 5 October. Players, club officials and even club mascot Rocky Robin got behind Mark's campaign to raise awareness of MND within the football community.

In the first week after launching, Mark's Story, a short video about life with MND, was viewed an incredible 25,000 times on our Facebook page (/mndassociation). Our challenge is to tell Mark's story through 300 match day programmes in England, Wales and Northern Ireland — a massive ask but with your help we can do it. Please spread the word through your branch or group Facebook page or newsletter.

Email football@mndassociation.org for a copy of Mark's awareness poster and templates to help you contact your local club and media. Or look at our Football v MND webpages www.mndassociation.org/football

If you have a contact at a football club, or would like to get your branch or group involved, please speak to your VDC or email football@mndassociation.org

At the time of going to press around 20 clubs had shown an interest in taking part in Football v MND, so help us reach our target of 300 match day programmes this season

Research News

MND is thought to be caused by a combination of subtle genetics, lifestyle and environmental factors. We know a number of genes that can cause MND, but there is less evidence for lifestyle and environmental factors.

Researchers in Australia have shown a toxin called β -N-methylamino-lalanine (BMAA), found in blue-green algae, causes proteins inside cells to clump and cause cell death.

When high concentrations of BMAA are present in neuron-like cells, BMAA substituted itself with the amino acid L-serine during protein formation, creating a faulty protein within the cell. These changed shape, clumped together, and could no longer perform their role within the cell. The researchers also found once BMAA was substituted into the protein the cells died.

If motor neurones are susceptible to BMAA this could give rise to potential new treatments.

RESEARCH published by scientists in Leicester looked closely at nerve cells and their ability to make proteins.

It showed that in a mouse model of prion disease (Variant CJD or 'mad cow disease'), chemically blocking a chemical known as eIF2 helped prevent disease development.

However, the chemical block, given to mice orally, had serious side effects. While it's a possible turning point for drug treatment for

neurodegenerative disease like Alzheimer's it's not the answer.

The processes involved in Alzheimer's Disease, prion disease and MND are not identical, but there is evidence that arimocloamol, a drug under development for MND works in a similar way.

Read more research news at
<http://mndresearch.wordpress.com>

Improving MND Care Survey



"Clear patterns have emerged from the survey, giving a strong, clear and unified voice from people living with MND. The results will help us determine our priorities for the next three years."

Sally Light, Chief Executive

AS you may be aware, we recently carried out an important survey of people living with MND called improving MND Care.

We received more than 950 responses, representing almost a third of people with MND in England, Wales and Northern Ireland, so making this the UK's largest ever survey of the views and experiences of people with the disease.

We are very grateful to all those who took part, including volunteers who helped shape the questions or who supported people living with MND in completing the survey.

Surveying people with MND every few years is vital so that we can see where care is improving, thanks to the combined efforts of our volunteers, staff, partners and supporters.

The findings also help us identify where services still need to improve, and therefore where we need to focus more efforts in the future. This will include how we best work with statutory services to raise the standards of care they provide, and also highlight where our own services can be improved.

Clear patterns have emerged from the survey, giving a strong, clear and unified voice from people living with MND. The results are helping us to determine our priorities for the next three years. The majority of people who took part chose to complete an optional section on end-of-life care. These responses will shape how we provide information, support and campaign in this important and sensitive area.

We will be sharing some top level survey results in your autumn edition of *Thumb Print* and will keep you up to date on how we use the survey findings to inform all areas of our work, including how you can use them to influence the valuable support you provide in your local area.

We are considering the best way to communicate the survey results and our future plans externally, to make the most of influencing and awareness raising opportunities.

Significant improvements since 2009:

People's ability to access and receive support with their breathing, in particular take-up of non-invasive ventilation (NIV). In 2013, 51% of respondents used NIV, compared to 13% in 2009. The experience of getting a diagnosis. For example, people having tests explained to them, the opportunity to ask questions and being given the news in a private place.

The number of people who have heard of MND by the time they receive their diagnosis.

The number of people who have a named person co-ordinating their care.

Because of us, 80% of people with MND now have greater awareness of the support available to them and 65% say their quality of life is better than it would be without us.

Focussing Our Efforts from 2013

Workings to further shorten the time to diagnosis, and influencing more neurologists, so people who have just been diagnosed, are referred to us.

Seeking improvements to social care.

Providing more information and support for people about the later stages of MND including end of life decision-making.

Challenging NHS and social care providers to better co-ordinate all the different services that a person with MND needs.

Improving the support available to family members and friends who care for people with MND.

While satisfaction with our services is high, we want to increase the proportion of people who give us a top rating.

Reforms Take Effect

THE Government's reform programmes have continued to take effect and in June the Government announced its spending round for the year 2015-16. Spending review

The Chancellor of the Exchequer announced £3.8 billion for social care in his spending review. Much of this had previously been announced and is not new money, but transferred from the NHS. Given that he announced steep cuts in other Government departments, however, it is a relatively positive outcome from the campaigning

work of the Care and Support Alliance, of which we are a member.

PIP takes effect

The new Personal Independence Payment (PIP) is now available across Britain, to provide help with extra costs arising from a disability for people under 65. In Northern Ireland, its introduction has been delayed from this autumn to spring 2014. As PIP is such a new benefit, there is a lot of interest and concern about how accurately it will meet the needs of people with MND

NHS in England

Changes to how specialised MND clinics are commissioned by the NHS in England come into force this month. We have been working hard to ensure that the specification used by the NHS for these services meets the needs of people with MND, and it seems clearer this will be the case.

Locally, we are working to support the many new NHS bodies to understand the needs of people with MND in their areas, including local Strategic Clinical Networks and Clinical Commissioning Groups.

To learn more about our campaigning work, join the MND Campaign Network,

Charter Postcards

How will you use new Charter postcards?

OUR new postcard is helping to promote and increase signatures of support for our MND Charter.

We now have around 13,000 signatures, and with your continued support we hope to achieve thousands more!

The cards can be given out at local meetings, events, in newsletters, or left on tables in GP surgeries, clinics, libraries etc. (with permission of course). Once completed, please return to the freepost address printed on the card.

Katy Styles included one with each of her Christmas cards.

Our members will receive a card in the autumn edition of Thumb Print. Branch secretaries and group contacts will receive 20 each with this edition of The News. If you would like more

Email campaigns@mndassociation.org or phone Tina Downs on 01604 611684

Events to enjoy in 2014

Jan 24th Burn's Night at binElla Faversham. More information on Page 8 and at:

<http://mnda-eastkent.org.uk/wordpress/?p=186>

Feb 23rd 11am Snowdrop Walk, Swarling Manor, Petham.

Swarling Manor is off Chartham Down Road near Canterbury and is easy to find, there is free parking and there will be hot drinks and homemade cakes .

The event is in aid of the Motor Neurone Disease Association (East Kent) and the Alzheimer's Society

Plenty of parking, disabled toilets, apologies no dogs. The stroll is not entirely wheelchair accessible.

For more information on page 4 or go to

<http://mnda-eastkent.org.uk/wordpress/?p=176>

Apr 27th Jerome Kern Show – Canterbury

Jun 14th Summer Ball

Swarling Manor is going to host a summer ball on Saturday June 14th tickets will probably be about £35 a head and include a drink on arrival, two course meal and music, there will also be a grand raffle on the day. Please book the date, more details will follow on the website next year.

Aug 17th Open Garden Stourmouth, more details in due course.

Sep 6th Awareness Meeting – Sturry

Oct 12th Soroptomists Choir Event

At St Mary's Church, Ashford where the tickets would be £5.00. More details will be posted in due course.

Support meetings: All meetings 11.00 – 13.00

15th Feb Red Cross Centre Folkestone CT19 4AY

12th April Thanet East Kent College

21st June Thannington

20th Sep Ramsgate

15th Nov Red Cross Centre Folkestone CT19 4AY

More details on all events

www.mnda-eastkent.org.uk

Branch Contacts

Chair	Wendy Sansom 01227 721627 info@mnda-eastkent.org.uk
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Association Visitor	Judy Keay 075 805 175 33 Judy.keay@mnda-eastkent.org.uk
Treasurer	John Hamer
Campaign Awareness	Katy Styles katy.styles@mnda-eastkent.org.uk
Committee Members	Hazel Watts, Jim West, Astra West, Joan Whitehead, Chrissie Batts, Mark Styles
Regional Fundraiser – South East	Pam Fry Pamela.fry@mndassociation.org
Thumbprint available online	www.mndassociation.org/membership
Online Forum	forum.mndassociation.org
National help line – MND Connect Mon-Fri 9.00 – 17.00 and 19.00 – 22.30	08457 626262 Local charge call mndconnect@mndassociation.org
Volunteering Development Coordinator	Annabel Lotsu 0845 375 1838 Annabel.lotsu@mndassociation.org

Association Contacts

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National Office	01604 250505 enquiries@mndassociation.org
MND Connect	0845 762 6262 mndconnect@mndassociation.org
MND Association Website	www.mndassociation.org
Offers support, information and advice to people living with MND and to health and social care professionals and volunteers	

binElla, the wine and champagne bar in Faversham, Kent will be holding a Burns Night on the Friday 24th January 2014. The aim is to raise much needed funds for the MND society.

The evening starts at 8pm with the jazz from Noel & Me. Haggis Neeps and Tatties will be served. Price £20 per person.

Tickets are limited and are available on a first come first serve basis. Please telephone 01795 530488 to book. Also, find us on Facebook <https://www.facebook.com/binellafaversham?ref=ts> to follow us and/or send a message.

We hope to see you at binElla for cool jazz and Haggis, Neeps and Tatties on the 24th.

binElla, Baltic House, Standard Quay , Faversham ME13 7BS, Kent

