

What Will Katy Do Next?

Katy Styles has had a prolific first half of 2014. As East Kent MND Campaign Awareness Officer, she has been meeting and working with many organisations.

Organisations include Government, local government, Churches and other institutions.

East Kent MND Committee members Katy and husband Mark Styles (seen below with Ed Miliband MP) have been extremely busy over the past few weeks creating awareness of MND with other persons living with the disease.



At the national councillor conferences, a small group of volunteers who are living with motor neurone disease (MND), including Liam Dwyer, Sarah Ezekiel and Mark Styles, took the opportunity to raise awareness of MND with a highly

impressive list of leading national figures, including the Prime Minister!

Between them, the determined campaigners met and spoke to the Prime Minister David Cameron, Mayor of London Boris Johnson, Labour Party Leader Ed Miliband MP and Communities and Local Government Secretary Eric Pickles MP.

Mark and Katy went to the Labour Councillor Conference to start the local election campaign. Other colleagues were at the Conservative councillors' conference. They had a fantastic weekend, together collecting over 130 signatures from MPs and councillors. Councillors and MPs were tweeted to come and see our stand. As it was a small event we were able to talk to lots of the councillors, leaders of councils, party leaders and

MP's. People who signed include Boris Johnson, Iain McNicholl MP, Hilary Benn MP, Grant Schapps.

More recently, Kent County Council has agreed to sign the MND Charter. Kent is the first County Council to sign as a whole.

This was achieved through writing letters, emails and meeting with local key decision makers. Thank you to those of you who sent the template letters to your councillors. Over 60 were sent out in the end. The combined effort worked and has got people who make decisions about Adult Social Care, people on the Health and Wellbeing Board amongst others, talking about Motor Neurone Disease, where they weren't before.

Kent County Council Sign Charter

On Wednesday 18th June Mark and Katy Styles were invited to lunch with Graham Gibbens, the Cabinet Member for Adult Social Care, at Kent County Council. This was to see him sign the MND Charter on behalf of the whole of Kent County Council. Kent County Council is the first county council in the country to sign the Charter.

Signing the Charter is fantastic news but better is that KCC is now committed to integrating the 5 points of the Charter into its new integration plans.

This would not have been achieved without the help of members and friends of MND in East Kent, sending out over 50 councillor



letters after the Spring Lunch. Mark worked until recently at Kent County Council, in Sessions House, where these councillors meet. Seeing someone with MND every day, coming into work, struggling with

the simple tasks we all take for granted, made everyone there more aware of the disease and its impact.

Graham Gibbens said "I do feel that this is a fitting tribute to Mark after 20 years of service in education and am also clear that this will benefit KCC to support people with a motor neurone condition."

"Signing the Charter means we will be supporting its principles. The implementation will need to fit with the Facing the Challenge and Transformation principles that we are now developing across Kent County Council and specifically within Adult Social Care."

Lobbying In Parliament

Mark and Katy Styles attended a lobbying event on behalf of the MNDA as part of the Specialised Health care Alliance in the House of Lords.

They managed to speak to Julian Brazier (pictured



left with Katy and Mark) our MP about specialised commissioning within the NHS and how many different hospitals and services they are involved with. People living with MND require many services and see many different consultants in many different

locations.

They discussed the frustrations of this and how the MNDA fund Care Centres throughout the country, which should be funded solely by the NHS.

It was great to meet up with other representatives from other rare diseases who all had the same issues about getting specialised care. They chatted to more MPs, informally throughout the day including MPs from Northern Ireland. They were all incredibly supportive of their work raising the profile of MND.

Fighting MND with Dad

<https://www.justgiving.com/fightingmndwithdad/>

At the start of this year our world was completely turned upside down. We were given the unexpected

and heartbreaking news that our Father has got Motor Neurone Disease (MND). None of us knew that much about the illness, the effects, a cure, or what was to come. To then be told it is a terminal illness and we only have a few precious months left with our dad was the worst we could have imagined. However our dad is amazing and has been so positive since the diagnosis. He has continued about his normal life overcoming or adapting to challenges he faces. We are as a whole family very proud of him and his positivity. His and mum's aim is to make as many people aware of MND and the symptoms along with raising as much money as we can for the East Kent MND Group. So all money raised will go to the local East Kent MNDA Group.

MND is a progressive disease involving degeneration of the motor neurons and wasting of the muscles. Early symptoms include...weakened grip, increasing slurred speech, excess saliva, difficulty swallowing, shortness of breath, tiredness, and leg/arm shakes. If you notice these symptoms ask to be checked, there is a lot of support available.

Over the course of the year we are holding lots of fundraising events and taking part in many different activities to raise money for our local MND Charity. We would love your support whether it be ideas, donations, or if you are already taking part in an event and haven't chosen a charity we would love you to choose ours.

Events to date have included a Charity football match and an abseil. David Irving shown above prepared to abseil.

Forthcoming activities include a sponsored walk from Faversham to Sittingbourne on Saturday 9th August and The Canterbury Half Marathon on 25th August. All support gratefully welcomed.

Since the start of the campaign the net effect has been to raise well over £2000 and the family have set themselves a target of £5000. We wish them well and are full of admiration for their approach to the news of their father's illness.



Summer Ball

The Ball was held at Swarling Manor, hosted by Valerie Lamb in aid of East Kent MND Association and the Alzheimer's Society. The evening was fine and over 120 guests attended the event which started with drinks in the rose garden, a three course meal, a raffle, an auction of prizes and dancing to a live band. There was also a brilliant magician called Chris Harding who went round the tables doing some excellent magic tricks! The events manager Philippa masterminded the auction and encouraged everyone to bid even auctioning off her husband to dance and an MND toy meerkat!



Several members of the East Kent MND Association committee attended including Judy Key (pictured above with Katy Styles) our Association Visitor, Wendy Sansom our Chairman and Katy and Mark Styles. Katy said a few words about MND at the event.

Chrissie Batts our Specialist MND Nurse also put together a table with friends.

A significant amount of money was raised and we are awaiting notification of the final total which will be divided between the two charities.

Our thanks go to Valerie and Christopher Lamb for their hard work and generosity in hosting this fabulous event.

Spring Lunch

MNDA East Kent held our first Spring Lunch last weekend on April 12th. The lunch was part of our ongoing support meetings held throughout the year. We had a wonderful turnout of 77 diners, who were treated to a fabulous lunch, an insightful speech and lots of fun and friendship.

Our lunch started with pre-lunch drinks at the bar/reception area, where we had a small information stand and a raffle stall. We sat for lunch at 12.30. Katy Styles welcomed everyone, thanked them for coming and pointed out some of the awareness activities being planned and worked on. Hazel Watts said Grace and then we were served our 3 course lunch.



After lunch, our Chairman Wendy Sansom introduced Sara Jane Murray, who gave a short and interesting speech about current activities at MNDA. Including such areas as support, awareness and research.

Wendy then thanked Sara Jane for her presentation and thanked everyone for attending and thanked various members of the audience for their efforts on behalf of MNDA. Finally she presented Sara Jane with a bouquet of flowers.

Hazel then drew the raffle and several people went away with fine prizes.

Mark Styles thanked the event's organisers, thanked everyone for coming and wished them a safe journey home.

Thanks to everyone who signed the local councillor letters arranged by Katy Styles, these are a most important element of our efforts to create awareness of MND among politicians and local government, the people who make the decisions that affect our lives.



The Spring Lunch organising committee of East Kent MNDA would like to thank all our guests for coming and supporting our Spring Lunch, Sara Jane Murray for speaking, East Kent College for the venue, food and drink and everyone who helped make it such a great success.

Awareness Meeting Sturry

East Kent Motor Neurone Disease Association Group (EKMNDA), is holding an awareness raising meeting in conjunction with the Beavers at, Sturry Guide and Scouts HQ, Park View, Sturry, Canterbury CT2 0NR on Saturday Sep 6th 11am to 1 pm.

This event organised by Brian Sackett, former Chairman of our Group, is supported by the Beavers Group led by Sarah Jones who are working towards achieving their Friendship Challenge Badges. Therefore, they provide the cakes and refreshments for the coffee morning and serve them and contribute to raising funds for a good cause.



Pictured is Gwen Pay, a supporter of this event for many years, with an MND display at Sturry Pharmacy. See also

<http://mnda-eastkent.org.uk/wordpress/?p=279>

This year Katy Styles our Campaigns Contact will talk on raising awareness and campaigning and we hope that parents of the Beavers and interested supporters of EKMNDA will attend.

Brian has also invited the Lord Mayor Cllr. Ann Taylor and the Sheriff Cllr. Tony Austin who have confirmed their attendance so that's a great opportunity for us to raise awareness of the needs of people living with Motor Neurone Disease.

We welcome as many supporters of EKMNDA who are able to attend to enjoy a coffee and homemade cake and listen to Katy who will tell us how we can all help raise awareness of MND in our local communities.

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 MNDA 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.

Repeat Showing of I Am Breathing

To end MNDA awareness month, Chrissie Batts, MND specialist nurse and the East Kent group organised a repeat showing of the film "I am Breathing" - the Scottish BAFTA award winning film of the final 9 months of Neil Platt's life. The film was being used to raise awareness of the

condition amongst healthcare professionals. The audience was made up of physiotherapists, trainee doctors, neuropsychologists, nurses from the local hospice and members of the hospital's ACAT team. Along side the film, the group was promoting the MND Charter and the new Red Flag Tool, a pamphlet written by the MND Association and RCGP. This pamphlet highlights those symptoms GPs or health professionals may see that should get them to consider a diagnosis of MND.



There was also a Bake It event, to provide refreshments for the attendees and raise some funds for the work of the MND. These included special medically themed cupcakes which went very quickly.

Thanington Support Meeting

Meeting on 21 June at Thanington Neighbourhood Resource Centre, Canterbury.



This was the first time we had met at this venue and there was excellent parking, access, refreshments and a large spacious room. Many thanks to all the thirteen attendees including Katy, Mark, Wendy and Judy from the local group committee.

Katy spoke to us about the events that she and Mark had attended to promote awareness of MND with organisations that can influence the provision of care.

They had visited the House of Lords and had spoken with the local MP Julian Brazier as well as MPs who are on the select committee.

The Archbishop of Canterbury has not yet signed up to the MND Charter, however the Church of England lead for health has.

One major success is that Kent County Council has signed the charter and will be aiming to incorporate the charter standards into their social care policies.

Mark and Katy asked for feedback on how many people had a named care manager and this prompted a useful discussion.

Katy explained that today was MND Global Awareness Day and everyone posed with a meerkat for a photograph which was tweeted that day!

Thanks John Hamer

Our treasurer is stepping down....and the EKMND Group committee members would like to say a big thank you to John Hamer (below) who has been our treasurer for the last seven years.

John has attended our regular group meetings and provided us with detailed spreadsheets of our financial situation as well as paying in monies from many different sources and writing thank you letters to the donors. He has spent many an hour watching television and counting out the contents of our pub collecting boxes! We are very sorry that he is moving away from East Kent and we wish him all the best for the future. He has handed over his role to Mark Styles.



Robert Blythe "Space"

Robert Blyth of Tunbridge Wells has written and recorded "Space" a piano album of 10 tracks in memory of Gareth Buckett, his former piano teacher who sadly died of MND in 2011.

This album will soon be available for you to buy for a donation of £5 to MNDA - East Kent.

Please click this link to hear "[Dreams of Better Places](#)" a beautiful track from the album. All proceeds apart from Postage/packing will be used to support people living with MND.

We have been fortunate to receive sponsorship to have 1000 of these CDs produced professionally.

Robert is 17 years of age and attends The Judd School in Tonbridge. He has always enjoyed composing and wrote all the pieces on the CD, over the past 4 years. Track 4 - Nocturne 1 was written as early as 2011.



In addition to composing Robert (pictured left) is an accomplished musician having reached grade 8 on piano and completed a diploma on French Horn.

Robert plans to study Maths at university and intends to continue composing and music making as a hobby. He also enjoys playing tennis and rugby.

Robert would especially like to thank Ian Stephens, head of music at The Judd School; Alex Harbourne for his help in recording the CD; Alex Metcalfe, his piano teacher; and his sisters Elizabeth and Rose for their help in designing the CD cover.

To date this CD has raised over £400 for MND and we hope to raise very much more in the coming months.

Please contact webmaster@mnda-eastkent.org.uk if you would like to be notified when stocks of the album are available.



Soroptomists Concert



St Marys Church
Ashford, Saturday
11th October 2014
at 7.30 pm tickets
£8.00.

The first half will feature David Green's Guitar Orchestra and Tessa Fineman's Love to Sing Choir will perform in the second half.

Tessa Fineman

Both are excellent performers and the Soroptomists would like to sell as many tickets as possible. Tickets will be available shortly from Astra West on 01233 626606.

All proceeds from the evening will go to MND in East Kent.

Fishing for MND

Fishing for MND Sat 5th July at Sandwich Lakes will commence at 8.30 in the morning with a peg draw to determine where you fish on the lake. Fishing will be from 10am until 3pm.

Entry is £20 some of which goes as prizes to the 1st, 2nd and 3rd placed competitors the balance goes to MND

Unfortunately at the time of going to press this event has not occurred, so we are unable to give any further details; however we will publicise the winners and funds raised on our web site in due course.

Bishop James signs Charter

We had great news during Awareness week, Bishop James Newcome (pictured left), the Bishop of Carlisle has signed the MND Charter. He is the Church of England's Lead on Health Care.

He speaks for the Church of England for all things to do with Health and medical ethics. This happened because we wrote to the Archbishop of Canterbury in January to ask him to sign the MND Charter.

This is the result many months later. The MNDA are pleased to have Bishop James' support at this time.

National Hydration and Nutrition Week

Chrissie Batts and Katy Styles represented the MNDA at this national event, held at Brakes Foods Head office, in Ashford. As part of National Hydration and Nutrition Week, people were encouraged to hold a tea party to make others aware of the importance of nutrition. Brakes have been developing foods for people who have difficulties swallowing or who have difficulties holding knives and forks.



Eileen Steinbock, Head of Health and Nutrition at Brakes Foods, wanted to support the work of the Motor Neurone Disease Association, as people living with MND have swallowing and nutritional problems.

Employees at Brakes were encouraged to have a cream tea, supplied by the company, contributing a £1 for each cream tea eaten. Colleagues were able to take time out of their busy schedules and meet up with other teams in their canteen. At Ashford an incredible £126.00 was raised. There were other similar events at Brakes throughout the country and the MNDA was the recipient of other monies from these Brakes afternoon cream tea events.

Thanks go to Ruth Casson and Cathy Amos for organising the event in Ashford.

Ray Terry - Rest in Peace

Donations totalling £564.56 have been received from friends and family following the funeral of Ray Terry. Angela, Christopher and Ben have especially asked that the money be used for research.

We are grateful to the Terry family for all their past efforts to raise funds for MNDA in East Kent.

Healthwatch Kent Signs Charter

Healthwatch Kent is an independent organisation



set up to champion the views of patients and social care users across Kent. They work to help local people get the best out of their local health and social care services. Steve Inett (right with Mark Styles), is the Chief Executive of

Healthwatch Kent and was delighted to sign the Charter.

Bake It Headcorn

All week the weather forecast was bad for Saturday. As a precaution we borrowed two small marquees and two gazebos, my theory being, if we prepare for bad weather it won't happen, and it worked!! Apart from one shower in the morning the day was warm and mainly sunny, even though there were reports of heavy rain in neighbouring villages.

With the help of some very good friends, we decorated the tables and marquees with orange, blue and white ribbons, and balloons, it all looked really lovely.

The cakes started arriving; everybody had made such an effort. Other stalls were an amazing



Kindle with John Taylor

We welcome volunteers

If you have a few hours a week you could spend working with us, we would be delighted to hear from you.

We need a minute secretary, who would be willing to send out agendas and minute our 6 meetings a year, then publish them to the committee.

We also would welcome somebody interested in social media to help us spread the word about our activities supporting people living with MND, spreading awareness and fund raising.

Please contact Annabel Lotsu, our volunteer co-ordinator at annabel.lotsu@mndassociation.org.

Forthcoming Events

Date	Event
Aug 9 th	Sponsored Walk Sittingbourne
Aug 25 th	Canterbury Half Marathon
Sep. 6 th	Awareness Meeting - Sturry Guide and Scouts HQ, Park View, Sturry Canterbury CT2 0NR at 11am.
Sep. 20 th	Support Meeting - Wyevale Garden Centre, Ramsgate. 11 am.
Oct. 11 th	Soroptomists Concert at St Mary's Church, Ashford where the tickets will be £8.00. 7.30
Nov. 15 th	Support Meeting - Red Cross Centre, Station Road, Folkestone CT19 4AY

More info www.mnda-eastkent.org.uk

tombola with over 100 prizes. My daughter-in-law Cathy suggested we had a Pimms tent, obviously the Pimms was free but we charged for the lemonade



and fruit! My daughter Nicola and grand daughter Jessica set up face painting for the children. Number one

daughter, Jane helped with the preparations in the days prior to the event and was a 'gofer' on the day, helping wherever it was needed. Other fund raising events were guess the weight of the cake; which was made, once again, by Hayley. Guess the name of the cow was the main attraction, dressed in MND colours (made by Nicola).

The prize was a Kindle. This was donated by the company I have worked for, for over 20 years - Mr Fothergills Seeds Ltd. The winner of the Kindle and the cow, was 7 year old Hendrix Turpin (Pictured left with Jean Taylor), who called her Cery's.

The day was very successful, we raised over £1,000, almost £200 more than we raised last year.

Jean Taylor - Headcorn

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The National Website offers support, information and advice to people living with MND, their carers, health and social care professionals and volunteers.