

Tyne & Wear Branch

Issue 17

October 2015

Registered charity no.294354

Our Ken Celebration!

A 90th birthday and over two decades of voluntary service could not go unrecognised, so on Saturday 18 July a special surprise tea party at the Northern Counties Club in Newcastle was held to honour Ken Hylton, our Branch President.

An inspiration to everyone at the Branch, Ken has volunteered for twenty-three years now, holding many different roles on the committee during that time, including Vice Chair, Chair, and Treasurer. Always actively involved, from attending committee meetings, giving a listening ear at support meetings, and holding buckets at street collections, to, until recently, assisting at the MND Association's reception tent for runners at the end of the Great North Run. In his mid-eighties he even courageously took part in the branch abseil event, joining hundreds of



other much younger participants making the hair raising decent down the outside of the Malmaison Hotel in the centre of Newcastle.

In recent years as Branch President, Ken has earned himself the unofficial title of 'Roaming Ambassador' personally attending many a cheque presentation on the branch's behalf and always following up the donations with a handwritten letter of gratitude.

Ken became involved with the branch when his wife, Peggy was diagnosed with MND and the family were supported with advice and equipment. Ken stated, "I

felt it a sense of duty to help because everybody is directly and indirectly is affected".

The special birthday tea party had been kept secret from Ken thanks to weeks of careful organisation and subterfuge by our branch secretary Marian Dent. The first he knew about it was on arriving at the club with club with Chris Noble, Volunteering Development Coordinator for the MND Association to be welcomed by the crowd of guests, members past and present from the Tyne & Wear Branch, the Northumberland Branch, and the Sunderland Support Group, along with staff from the Newcastle Care Centre and Kens family who had all arrived early to help with the special surprise. Looking astonished Ken later confessed, "It is the greatest surprise of my life".

After a delicious afternoon tea speeches were given. Martin Boyes, Chair of Tyne & Wear Branch took the opportunity on behalf of the branch to recognise Ken's 90 years, taking us back in history to events that happened in the actual year of Ken's birth. Then he thanked Ken for all the work he has done in service to the branch over the years, reminding us of Ken's often said comment that "if someone is willing to give us money then I am more than happy to turn up and collect it". As Martin stated "to say Ken is a hard worker is an understatement".



Chris Noble, Volunteering Development Coordinator for the MND Association presented Ken with his MND Association Long Service Award certificate and pin badge, celebrating his twenty years' of service. Chris said, "Ken is a perfect example of our MND Association values in everything he does and gives personally as a

volunteer in the support for people with MND. On behalf of the MND Association I would like to thank you for everything you do Ken."

In his thank you speech Ken said "I am grateful to you all, and it's absolutely wonderful to attend this event" and talked about meeting his wife Peggy, becoming engaged, getting married and having a family, and how Peggy (knowing his love of music which had developed as a child) had assisted him in getting involved in a choir, which he still enjoyed. Ken was given gifts and cards from the Branch, then glasses were raised and Happy Birthday sung.

Marian was congratulated with a round of applause for all her hard work organising such a lovely event, and there was great relief all round that there was no longer a need to keep it a secret from Ken any longer!

Ken is an absolute treasure." member of the Sunderland Group

"Ken has been at every MND meeting... Has an immense interest in every person he meets... He is the role model for everybody at the charity and at the centre... He is affectionately known as Captain Mainwaring.

Francis Kelly MND Clinical Nurse.

"I met Ken 18 months ago; he has a nice lovely approach and worked hard in the Tyne and Wear Branch." John Fielding Association Visitor volunteer, Northumberland.

Our Mary



It was with great sadness that we heard in July that one of our long serving branch committee members, Mary Garbarino, had died.

Mary became involved with the MND Association when she lost her sister to the disease nearly 25 years ago and she had been loyally volunteering with us ever since. Whatever the event, you could count on Mary to help. Coffee mornings, street collections, awareness stalls and at the annual MND memorial service.

Every year she volunteered at the Great North Run

(GNR) reception tent on the drinks and food. Trudi Sadler, Events manager for MND Association, said that the GNR was certainly not going to be the same without Mary “I have truly valued her kind support throughout the years I have managed this event and will miss her ‘cheeky’ side” Anita Solan, Community & Events Fundraiser also remembered Mary’s humour “She was a formidable lady, a wonderful volunteer and very funny too!”

Her volunteering work was not just with the MND Association; she also volunteered with the league of friends at North Tyneside Hospital, and helped out in charity shops and the community furniture store through her church.

Mary was *very* camera shy and was *very* successful at dodging the lens whenever it was pointed in her direction. Thankfully we have this one rare snapshot in the scrapbook of her behind a stall at the Tyne & Wear branch coffee morning at Brunton Park back in 1997. Much loved and greatly missed by us all.

Remembering the Lads



In August the employees from two Wallsend engineering firms, Barrier Group and OGN, got together to host a charity football match at Hebburn Sports and Social Club in memory of Adam Peacock and Keith Hallway, who both lost their battle with Motor Neurone Disease..

The two men had both been keen football players, Keith playing for Hebburn Home Town Football Club and Adam playing for South Shields FC Graham Brooks, Construction Manager at OGN Group said “We thought it fitting to help raise funds with what is shaping up to be a rather competitive game of football.”

It was a fun family afternoon out for all involved, raising £4,000 for the MND Association. The money was raised through donations, entry fees from the spectators to watch the game, and a raffle with prizes donated by local businesses.

This is becoming an annual event for the two firms who are already looking forward to their return game next year.

The Berwick Big Splash!

It’s hard to believe last year for three crazy weeks just about everybody was

taking part in the Ice Bucket Challenge (IBC), and if they weren’t personally taking part themselves they surely knew someone who was. All ages were pouring iced water over their head from bins, washing up bowls, and beach buckets, and then putting videos and nominations onto their social media Facebook and Twitter accounts.



The event caused such a storm with many celebrities and sports personalities also getting involved. It raised over £7million and most important of all was hugely instrumental in raising much needed awareness of motor neurone disease.

This year for MND Awareness month in July, Berwick-Upon-Tweed businesses, residents and even town councillors got behind a new fundraising and awareness drive resurrecting the IBC thanks to the inspiration of our most northern MND Association volunteer, Colin Hardy. Colin Hardy experienced the challenges of MND after witnessing his sister, Pauline Scott passed away just three months after

being diagnosed with the disease, last year. His loss has been source of inspiring Colin to raise funds to find a cure. As Colin explained in July, "Last year we had great success with lots of people doing the ice bucket challenge for MND that really helped raise awareness'

"But the problem hasn't gone away and we haven't found a cure for it so we need to do more and I'm hoping to get as many people as possible from Berwick to get involved Now into October there have been 20 events around the town, and over £4000 raised. The last event involved the actors from this years pantomime at the local theatre in their costumes. Many have expressed an interest in doing more next year so Colin hopes to grow the event into an annual awareness opportunity within Berwick – and perhaps wider in Northumberland

2015 Great North Run

It was yet another amazing turnout for the MND Association at this year's Great North Run. We had 280 participants from all over the country each doing their bit to raise vital funds and awareness. Competing alongside 57,000 others they ran the memorable 13.1 miles from the centre

of Newcastle to the sea front of South Shields.

Although a beautiful sunny day for spectators and supporters, the warmer conditions did make it a bit harder for some of the runners.

There was a zestful buzz of anticipation amongst the families and friends of the runners as they waited at the MND Association's hospitality tent at the end of the run. Members of the Tyne & Wear Branch had turned up as always to help members of the MND Association Community Fundraising team in the annual 'meet & greet' and provision of refreshments for the runners. Branch chair, Martin Boyes and his wife Karen kept the beverages coming, whilst branch secretary Marian Dent helped capture pictures of our runners as they made it over the finishing line.

Alanah Gelling, Community Fundraising Coordinator with MND Association welcomed participants waving her MND Association maracas and congratulating runners on their efforts. "There is always an eager anticipation and excitement for the runners to return. We are thankful for their hard efforts and make sure they are appreciated"

Sadly, because of her new exciting promotion to Events manager for the MND Association's, this was Trudi Sadler's, last time at the GNR tent. Trudi has covered the event for the last five years. "We get to meet so many inspirational people, who without their support, we would be unable to do the work we do. It's a real pleasure to be able to thank them for their kind support, congratulate them on their huge half marathon achievement and show our appreciation." As always, many of our runners were participating in memory of loved ones and friends with the disease, and carrying their names and photos on their running vests as inspiration to keep them going.

Some were brave enough to even 'dress up' for their run, such as Craig Thompson as superhero 'Dandy' Bananaman, Jasmin Boyes and Sam McVey as MND Ghostbusters, and sisters Annette Robson and Karen Whelan in their individual style of bright orange wigs and tutus, collecting donations on their way

There was even time for some birthday celebrations with photographs on the tent walls for James Worrel and Jeremy Wright.

The MND Association's official tent photographer

Alan Riddle was there to capture the triumphant completers. Alan, a volunteer since 2003 came along one year with his camera to photograph the volunteers and then thought he would photograph the runners as they arrived. The photos were then put up on the Tyne & Wear branch website for the runners to see and this now happens every year. Alan does his best to capture everyone. "What started as a novel idea has now become an integral part to capture the event" he said. The day was completed with the Red Arrows bringing their spectacular red white and blue display to the event as always.

Fancy a personal challenge for 2016? How about setting yourself the goal of taking part in next year's GNR and help raise vital funds and awareness for MND. You can either enter yourself for a place as a runner or apply for one of our allocated charity places through the branch. Contact branch secretary Marian Dent to register your interest.

Some of the runners, their times and their motivation Gethin (1hr 31min) and Sian Jones (1hr 41min), Sian's uncle, Raymond, had MND. The couple starting running 2009. "Now we try to enjoy life and not take it for granted. Raymond was hard working and had his

own business, he popular man amongst our community and very generous; he fought strongly against the disease. We tried to spread more awareness of MND through the local area. We've enjoyed the fantastic charity work and doing something positive. Hopefully one day there will be a cure."

Helen Barber (1hr 41min) her aunt had MND. "The event is a way of raising awareness and funds for research, as little is known about MND. Until we find a cure, there is no finish line, and we'll keep on fighting and doing more". Helen decided to complete fifteen events over 2015 to raise awareness and funds for the Association. The GNR was Helen's twelfth event, and just the week before she had participated in a bungee jump!

Professor Ken Durose, (2hr 20 min) His first time running in the GNR. "Normally I do the photos, and I thought I would run this year". Ken's father-in-law had MND. He has a novel way of raising awareness and funds by selling tea to walkers at the top of mountains from his bike.

Ted Ferguson time (1hr 43min) It was great to see Ted again. His 23rd GNR! Ted has been running for MND since his brother

Philip was diagnosed in 2000.

David McCaulay and Rosalie McSwiggan, (2hr 37mins). Rosalie's sister Maria had MND. David got Rosalie into running with the London Marathon and this was their 8th GNR. David and Rosalie climbed Kilimanjaro with friend Eric. They have been fundraising since 2003. David even ran the West Highland Way 95 mile run lasting 24 hours. "We're so glad to do this as it's for a good cause and hopefully we can find a cure" Maria's daughter Nicole and her boyfriend also ran the race.

For a pictorial review of the day and to see our gallery of runners please go to our branch website.

<http://mnd-tyneandwear.org.uk/great-north-run-review-2015/>

York Regional Conference



The regional conference was held at the Royal Station hotel. An all-day event focusing on the latest news in care, campaigning and research. The event allowed people with MND,

family member's friends, volunteers and people with a personal or professional interest in the MND Association to hear all about the latest about the work of the charity.

For those of you who have been members for a while, these replace the MND Association Spring conferences. They have been held throughout the year at varied regional locations to enable as many

Personal Stories

people as possible to attend. All of them were broadcast live online so everyone had the opportunity to hear the latest news in care, campaigning and research. If you missed the York Conference you can still watch the recorded version online <http://livestream.com/events/treamingcompany/mnda>,

Presentation on the day include Francis Kelly on

The role of MND care centres for people with MND and the personal perspective of Colin Hardy on his role as Campaigns Contact for Northumberland Group.



Silver Band Concert in Aid of Motor Neurone Disease - Catherine Sweeney

Almost 2 years ago we were devastated with the news that my husband John had been given the diagnosis of Motor Neurone Disease at the age of 47. Having to tell our 2 boys, Adam and Ben (at the time aged 8 and 11) that their father had MND, was probably the worst news that I have ever had to break to anyone. The boys are fully aware of MND and since have become big supporters of MNDA.



and we have made some amazing supportive friends.

Back in February my youngest son Ben joined the People's Mission Junior Band, as he plays cornet. I joined the People's Mission Senior Band as a flugelhorn player. The bands are both run by People's Mission Church at South Shields,



When members of the junior band found out that Ben had decided to do the Walk 2 d'feet MND they decided to join Ben, and even held a mini concert at the half way point. Junior band really encouraged him and kept him going on his walk, taking photos with mobile phones and selfie sticks.

In total Ben managed to raise £462 and junior band another £140 on top of that! People's Mission support didn't stop there. One Friday night at band practice we were told that People's Mission Bands had chosen to support MNDA in their annual summer charity concert. I managed to hold it together until I broke the news to Ben in the car. We found it really quite overwhelming

that we have such supportive friends and was quite an emotional moment. Quite ironically the concert was held on my husband's birthday, so Ben had great pleasure in telling his dad he was taking him to a MNDA charity concert for his birthday.

The concert took place in the People's Mission Church. The junior band were the real stars of the

show. With an average age around 10 years old, they were fantastic and it was Ben's first concert playing his cornet. Their favourite pieces consisted of Pirates of the Caribbean and James Bond. It was also total luck that I also managed to hit the high notes of my solo "How great thou art".

The emotional point in the concert was at the end

when we played "you'll never walk alone", while selfies taken by the children on their sponsored walk were displayed on the large projector in the church. I don't think there was a dry eye in the band. The concert managed to raise £550 in total going to MNDA. We would personally like to thank People's Mission for all the help and support they have given us.

Dragon Slayers raise money for MND - Angie Rendal



(in a field), we would have a bucket collection!

One of our members (Gordon) had just had a knee operation was using a mobility scooter, so we

I decided to raise some money for MND as this disease has affected my family in a big way and as I am a member of the Dragon Slayer's MCC I decided that at one of the bike rallies in the summer

decorated it with MND balloons. He had the collection bucket on the front and went round the camp site collecting money using a toy gun! There was another collection bucket at the check in tent. Myself

and my husband Ian went round the function room on the Saturday night shaking the bucket and everyone all put their hands in their pockets for us. It was a great night and we had a good chat and laugh. Altogether we raised £400!

Many thanks, to Angie and the Dragon Slayer's MCC, for their support and generosity. (We are not sure about the use of the toy gun though Gordon!)

National Make benefits work for MND



We need your help to make

sure the Government's plans to reform benefits do not have a negative impact on people with MND and their carers.

If the Government's current proposals in the Welfare Reform and Work Bill 2015 are passed and become

law, it could take vital support away from people with MND who claim Employment and Support Allowance (ESA), a benefit to support them when they can no longer work. It is unacceptable to expect people with MND who will

face rising costs as their illness progresses, to manage with less as a result of these reforms.

Find out more about the impact of the Welfare Reform and Work Bill on people affected MND by reading our [briefing paper for MPs](#).

Share your experience of claiming benefits

<https://www.surveymonkey.com/r/ESAclaims>

Your MP can help change this. Please email your MP now and urge them to speak up for people with MND and their carers.

If you, or someone with MND you know, has claimed Employment Support Allowance (ESA) or Personal Independence Payment (PIP), tell us about what it was like.

Share your experiences by clicking on the links below.

<http://e-activist.com/ea-action/action?ea.client.id=1871&ea.campaign.id=4235>

We will use your examples to help inform our campaigning and influencing work, and all examples will be anonymous.

<https://www.surveymonkey.com/r/PIPclaims>

MND Association attends the party conferences



People affected by MND have represented the Association at the Labour and Conservative Party conferences for the first time.

We attend the main political party conferences each autumn to raise awareness of MND and some of the issues people with the disease face. This year we co-hosted a fringe event on end of life care at the Conservative conference

with charity colleagues Marie Curie, Macmillan Cancer Support, Sue Ryder, Hospice UK and the National Council for Palliative care.

Greg Broadhurst, whose grandfather died after being diagnosed with MND, joined us at the Conservative Party conference in Manchester last week. Greg is the Campaigns Contact for the Manchester Branch. He spoke to a number of negotiating so-called 'Devo-Manc' with the Government including the devolution of health and social care budgets to local decision makers.

David Setters, who is living with MND, attended the Labour Party conference in Brighton at the end of September. David, who is the Campaigns Contact for the East Surrey Branch, said "I'm a fairly apolitical person but I must admit I did find the conference very enlightening in terms of how people view health and social care issues and charities in general".

David attended a number of fringe events and met Shadow Health Secretary Heidi Alexander MP who requested a further meeting with David and the Association in Westminster

MND Research

MND research newsletter



About the newsletter

Our 'What's happening in MND Research?'

newsletter is a quarterly communication with people living with MND who are interested in getting involved in MND research. The newsletter is published at quarterly intervals (July, October, January, April) and is sent to people living with MND on our MND Research list.

[Click here to download and view the current issue of 'What's happening in MND Research?'](#)

Request a hard copy of the newsletter by contacting the Research Development team on 01604 611 880 or research@mndassociation.org

The MND Research list

Our MND Research list is a list of people living with MND who are interested in getting involved in research. If you would like to be added to the list [please click here](#).

Please note: If you are already on our MND Research list, but do not wish to receive the newsletter, please contact the Research Development team on 01604 611 880 or research@mndassociation.org

I'm not on the MND Research list, can I receive copies of the newsletter?

Yes, If you are not a person living with MND, but would still like to receive the newsletter to be kept up to date with the latest MND research news and opportunities to get involved in research, please contact the Research Development team on 01604 611 880 or research@mndassociation.org

New module for care workers



We have launched a new [online module](#) for care workers, which covers [motor neurone disease \(MND\)](#), its symptoms, and the support a care worker

can give to a person with MND.

Developed in partnership with the University of Northampton and a panel of health and social care professionals, this introductory level module is split into six units:

- Introduction to MND
- Eating and Swallowing
- Breathing

- Moving
- Thinking
- Communicating.

Each unit takes around 15 minutes and can be studied individually. This allows the module to be completed over a number of sessions. People who complete the module will receive a certificate of completion.

We hope this resource will help care workers better understand the needs of

people living with MND and their families.

Visit:
www.mndassociation.org/ca/reworkermodule

07/09/15

Raise your mugs with Tea 4 MND

Fundraiser Pete Collins is celebrating after his Tea 4 MND campaign reached over £4,400.

It was launched in September to raise vital funds and awareness for the Association by highlighting how difficult simple tasks like making or drinking a cup of tea can be for people living with MND.

The campaign has inspired many people to get involved, including several celebrities. There was even

a group photo taken at our recent AGM!

Share your 'creativiTea' by joining in and following these easy steps...

1. Make a Cup of Tea
2. Take a **#SelfTea4MND** (A 'selfie' with your cup of tea)
3. Make a donation using TextGiving or JustGiving – Text 'TMND55 £5' to 70070 or go to www.justgiving.com/Tea4MND
4. Nominate your friends, family and work colleagues to get involved.



Follow Tea4MND on [Facebook](#) and [Twitter](#) or by using the hashtag **#SelfTea4MND**

Useful Contacts

Branch Contacts

Martin Boyes, Branch Chairman, tel: 0191 548 5847,

Ken Hylton, Honorary Branch President & Vice-Chairman, tel: 0191 236 5838

Marian Dent, Branch Secretary, tel: 07922628417 email: general@mnd-tyneandwear.org.uk

Tyne & Wear Branch website

<http://www.mnd-tyneandwear.org.uk>

<https://www.facebook.com/#!/groups/tynewearbranch/>



MND Association Contacts

Regional Care Development Adviser – Jenny James – 03453 751820,
jenny.james@mndassociation.org

National Office – 01604 250505, enquiries@mndassociation.org

MND Connect – 03457 626262, mndconnect@mndassociation.org

MND Association website – www.mndassociation.org

Registered Office:

Motor Neurone Disease Association, David Niven House, 10-15 Notre Dame Mews,
Northampton, NN1 2BG

Registered charity number 294354

mndconnect
03457 626262
mndconnect@mndassociation.org