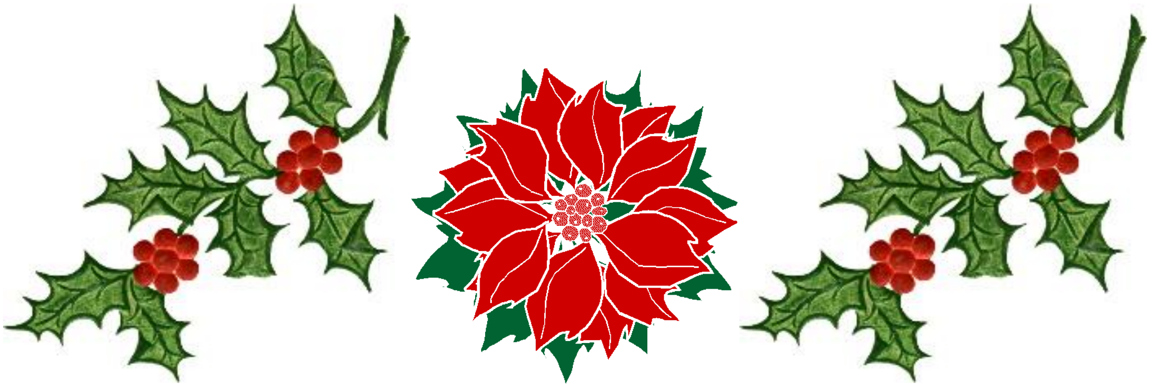
Newsletter

Northamptonshire Branch

DECEMBER 2015



A warm welcome to the winter edition of our branch newsletter bringing you local news and information

FUNDRAISING

Coffee Morning Saturday October 24th

A very successful Coffee Morning, attended by about sixty people, was held in Wollaston raising an amazing total of £943.95 for the Northants Branch this did include £291.80 of MND Christmas Card sales. We sold lots of cakes, ran a great raffle with some lovely prizes.

Mike Hollowell a local gentleman living in Wollaston has written and published a book entitled ‘The Pig That Squealed’. The book is a collection of thoughts and reminiscences of life in rural Northamptonshire from 1935 to the mid 1950s obviously covering the times through the Second World War. The cost of the book is £7 with Mike donating £2 of every copy sold to MND. Mike came to the coffee morning and signed each book that was sold.

Our grateful thanks go to all who baked cakes, donated raffle prizes and to all who came to support us.

Kate Inchley

Charity Ale and a Shave night in memory of Stewart Smith who bravely fought MND until he lost his battle on 27th November 2012.

On 24th August 2015 Christian Wiles Hairdressing, based in Northampton, hosted a charity evening in memory of one of their very special clients, Stewart Smith. Christian Wiles and his family are family friends and have been for many years. Christian has shown great support in fundraising since dad was diagnosed with the disease, and has donated prizes for raffles on many occasions. He then chose to host a charity evening to raise funds for the Northants branch of the MND Association.

Publicised through his salon, men were invited into the salon to enjoy music, ale and traditional gentlemen’s grooming. Those attending the evening paid for the services on offer and ALL the proceeds donated to MND Northants branch. The evening saw a great turn out, and Christian presented me with a cheque for £700 for Stewart Smith branch tribute fund.

Ali Buttress

Cards for Good Causes




Dave and myself have volunteered at **Cards for Good Causes** for 15 years, in many various venues. This year we are in All Saints Church in the centre of Northampton. It is a beautiful Church and whilst we were there on Monday the organist was practicing and it was magical. We look forward every year to meeting familiar faces plus meeting new ones, customers and volunteers. Pop in and have a look or maybe volunteer, they are always looking for people to help. We help because they sell MNDA cards.

Jackie and Dave Atkins

CHANGES AT DAVID NIVEN HOUSE

(Head Office of MND Association)

About Me

I'm Anika, the new social media co-ordinator for the Northants Branch of the MNDA. I'm twenty-three, born and raised in Northampton and studied biomedical material science at the University of Birmingham. I am currently doing a scriptwriting course and enjoy creative writing. After using social media for personal and social use I decided to put the skills to a notable and worthy cause. The use of social media helps promote and raise awareness of MND in order for the people living with MND to be recognised by wider society.

I was fortunate to attend one of the drop-in meetings at the garden centre where I met all the wonderful people from the Northants branch and saw some of the amazing work

they do. Volunteering has been a rewarding experience so far and has opened my eyes to the amazing work carried out by the association.
The aim is to build the social media community and have it as a means for people to communicate with one another and post about fundraisers or events within the Northants area, allowing the community to get involved. Please like the Facebook page if you would like to know what’s coming up and get involved.
Check out the Facebook page at: https://www.facebook.com/MNDANorthantsBranch
You can reach me directly via email at: anikap36@yahoo.com.

Head of Education and Information

The purpose of my job is to lead the development and implementation of the Association's education and information programme, meeting the learning needs of health and social professionals supporting people with Motor Neurone Disease.

So far I've been gathering information which will inform our education strategy - I've liaised with the education programme manager at Parkinson's UK and plan to visit the Alzheimer's Society soon to learn about the work they do. I'm also considering a survey and focus groups to ensure views of stakeholders are captured.

I'll be off to the Allied Professionals Forum and the International MND Symposium in Orlando next month. Leading researchers, academics and clinicians from all over the world will gather to hear about the latest developments in research and care. I've already been asked to 'blog' my first impressions by the research team!

Another part of my role is to lead the team which develops, writes and reviews all the Association's publications for people with MND, carers and professionals. I have been getting to grips with what they do - they recently won the British Medical Association award for best patient information publication of the year, so I feel very privileged to be working with such a dedicated team.

Rachel Boothman

Joan Randell (AV) with Rachel (RCDA) when she joined us at the drop-in support group in October before taking up her new post as Head of Education and Information.

Regional Care Development Adviser (RCDA)

I graduated from Leeds University in 1991 with a degree in Ecology and, although that was my passion, I almost immediately 'fell' in to volunteering for a local HIV charity. Friends of mine had become HIV+ and, much as is the case with MND now, treatment options were limited and public awareness was low. For my first few years with the organisation, I staffed the Helpline, ran drop-ins for HIV+ people and their families, delivered educational events and set up a resources and information library.

I carried on as a full-time volunteer until 1994, when I successfully applied first for the post of 'Events Worker' – staging awareness and fund-raising events and then later as Health Promotion Worker for HIV+ people, managing a team of volunteers. In 1998, I left Leeds to take up a manager's post in a similar NHS /voluntary organisation in Portsmouth and then in 2001, returned to Leeds – this time as Regional Director of my 'old' work place – which by this time had amalgamated with a larger organisation called the Terrence Higgins Trust (THT).

In 2003, I left THT, intending to take a year off and do some travelling, but after only a couple of months was called back to the UK, to Northampton as my mother-in-law was very ill and had been given a prognosis of 6 months. It soon became apparent that at least some of the problem was that she had Alzheimer's disease and was unable to self-care. We sold our house in Leeds and moved permanently to Northampton and cared for my mother-in-law in her own home until she died in 2010.

In January 2012, having decided that our future lay firmly in Northampton, I was appointed as Manager of the MND Connect Helpline service at the Motor Neurone Disease Association, and that is what I have been doing until my recent appointment as RCDA for Central Midlands.

So! Quite a varied career, but I hope that my own experiences of volunteering in the palliative care field and the many years that I have spent supporting volunteers will stand me in good stead. My time managing the Connect team has given me a thorough 'grounding' in MND and the Association and I hope that even though I may not always be able to immediately answer every question put to me, I will probably know someone who can!

I am looking forward to meeting all the AVs and Branches and Groups in the Central Midlands 'patch' and working together with you to improve the care and support of people affected by MND. I realise that Rachel Boothman is a hard act to follow, but I shall do my level best!

One final observation: when I started working in the field of HIV all those years ago, people only received a diagnoses when they started showing symptoms, there was no effective treatment and life-expectancy was very poor – a situation not unlike that of MND today. In the mid 1990's, the 'breakthroughs' started: testing became widely available, new drugs were developed and improved upon and the prognoses got better and better. Today, someone receiving a diagnosis of HIV in this country might expect to live a normal, healthy lifespan. Although MND and HIV are very different diseases, having witnessed this transformation once, I firmly believe the breakthroughs in MND will also come and we will beat this condition.

Scott Maloney

Silverstone Motoring Fan With MND Meets Racing Legend

Author: Bethany Robertson ABOUT MY AREA WEBSITE for NN12 area Published: 4th November 2015 11:55

Craig Sarson and Tom Sarson

A MOTOR-racing fan, who is living with motor neurone disease (MND), met a racing legend at Silverstone on 1st November. Craig Sarson, from Silverstone, was invited to watch the final of The Walter Hayes Trophy – a race weekend which features Formula Ford 1600 cars.

Australian racing driver, Chris Davison and his brother, Richard, were promoting the work of the Northampton-based Motor Neurone Disease (MND) Association by running logos on their cars and spent a lot of time talking to Craig and his sons while showing them around the garages and pit lanes.

Craig said: "Being diagnosed with MND was a bombshell, it has changed everything. I hadn't even heard of it until I was diagnosed. I am now in a wheelchair and have had to pass my business over to my sons. "I have lived in Silverstone for over 30 years and have spent a lot of time going up to the circuit. We had a brilliant day on Sunday, it was very interesting."

Chris and Richard were also promoting Racing4MND – a fundraising website set-up by former racing driver, Neil Cunningham who is also living with the disease, while another driver, Neil Tofts, chose to offer his support as his friend Phil Newby has MND. Chris said: "Both my brother Richard and I are in our 60s and our real racing days were many years ago. But we have always harboured a desire to race overseas at some stage in our lives, and this was the year.

"Things changed dramatically in my life in February 1988, when my wonderful wife Jan suffered a very severe stroke, leaving her with major disabilities for life. I am her sole carer, but receive enormous support from family and friends along the way. Her situation made me very aware of people who are afflicted with major health problems, and I like to help where I can. My daughter Claire, who now races historic Formula Ford cars with us, has developed a stroke awareness initiative called FF/FAST, and with the support of the Australian Historic Racing Group, many of our historic Formula Ford cars are running her FF/FAST stickers.

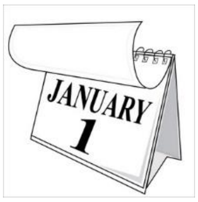
"As I had become aware of the Racing4MND program through Neil, an old racing buddy, I thought our visit to Silverstone may give us the opportunity to repay the support we have had over the years by carrying the MND logos on our cars." James Beckett, who runs the annual event, said: "Neil Cunningham is a true hero of Formula Ford and we were pleased to be able to support Racing4MND and the work of the MND Association by running the Association's logos on our cars. As ever, the atmosphere was incredible and the 5,000 spectators were treated to some fantastic racing."

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND. It is the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

The charity improves care and support for people with MND, their families and carers. It funds and promotes research that leads to new understanding and treatments, towards a cure for MND. And it campaigns and raises awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

In Northamptonshire the local branch of the MND Association holds regular support meetings, informal drop in lunches and fundraising events.
For more information see facebook.com/MNDANorthantsBranch or mndnorthants.org.uk

DATES FOR THE DIARY



2nd December 2015 Lunchtime Support Group (see page 8)

13th December 2015 Christmas Buffet (see below)

6th January 2016 Lunchtime Support Group (see page 8)

3rd February 2016 Lunchtime Support Group (see page 8)

14th February 2016 Open Meeting 2.30pm -- 4.30pm at St Matthews NN1 4RY

2nd March 2016 Lunchtime Support Group (see page 8)

13th March 2016 Silverstone Half Marathon
(details from Stephanie.steward@mndassociation.org)

6th April Lunchtime Support Group (see page 8)

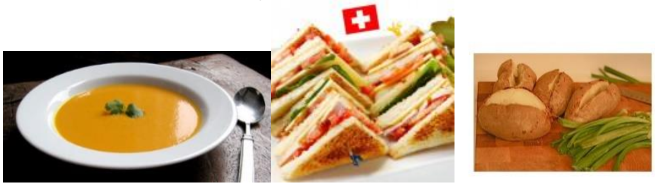
10th April Northants Branch AGM 2016 2.30pm--- 5pm at St Matthews NN1 4RY

Christmas Party Buffet Lunch

To be held on Sunday December 13th 2015
1.30pm --- 5pm
Venue St Matthews Church Parish Centre
27a The Drive
Northampton NN1 4RY.
The cost is £4 but is complimentary to people living with MND and their carer.
People having difficulty swallowing will be catered for. We will be holding our usual raffle, Peter will have Christmas Cards for sale for last minute shopping.
Our entertainment this year will be “” Open Stage “” a choir in which Kevin, a committee member, is a singer and we look forward to that.
All are welcome it will be lovely to see you there whatever time you can make

LUNCHTIME SUPPORT GROUP

We hold an informal lunchtime get together
for anyone affected by MND
This is an opportunity to meet and share experiences



Soup, or a toasted sandwich, or a filled baked potato and coffee or
tea are free to anyone with MND and their carer
We meet on the first Wednesday of each month in the restaurant
area of the Garden Centre in Wootton, Northampton NN4 6HP
There is no need to book but please arrive by 11.45
so that your order can be taken

Ian Bealing and his wife, Margaret regularly attend the drop-in meetings held by the Northamptonshire Branch of the Association at a garden centre in Northampton. Margaret was diagnosed with MND three years ago and Ian cares for her at their home in Rushden. Ian explained that he found it interesting to see how others were coping with the disease and found it comforting to know that they are not alone. He said: “I consider us to be very fortunate as Margaret’s progression appears to be slow. MND does not affect any two people in the same way and it is interesting to see that. “We get a lot of support from the group and comfort in knowing that there are people here who are going through the same things.”

The branch’s chairman, Kate Inchley, said the drop-in session was very successful and put it down to their informal nature. She explained: “The idea for the drop-in session came from Chris, a lady who is living with MND. “She was finding that she was the only person with MND who was attending our regular meetings and wanted to find a way of encouraging more people to come along. “With some support we managed to get the drop-in session and it has proved to be very successful – we get between 12 and 20 people attending each time.”

(Extract from Thumbprint – Autumn 2015)

SERVICES EXPLAINED

National Office

Motor Neurone Disease Association, PO Box 246, Northampton NN1 2PR
Telephone: 01604 250505

Membership – This is free to people living with MND and their carer. As a member of the Association you will receive a membership card, our regular magazine *Thumb Print,* full of information - the latest news in care and research, as well as features on how some families cope daily with MND. Automatic link to your nearest branch/group and opportunities to get involved at a local level. Invitations to the conferences and seminars we organise. Our *Annual Review/Impact Report* which outlines our progress made over the last financial year and our plans for the year to come. Full membership also entitles you to elect Association trustees and vote at the Annual General Meeting. If you are interested in becoming a member, please contact MND Connect

MND Connect – 08457 626262 - a helpline available Monday - Friday 9am -5pm, 7pm - 10.30pm (charged at local rate) and email service mndconnect@mndassociation.org. Provide advice on all aspects of MND. They can also post information about MND and support available

Regional Care Development Adviser (RCDA) Scott Maloney – 07501682095 scott.maloney@mndassociation.org – assisting with advice and support on care management and service development in your area.

Volunteering Development Co-ordinator (VDC) Neil Penson 01604 611686
neil.penson@mndassociation.org VDCs work with existing branches and groups to develop and build on good practice. This includes the recruitment and induction of branch officers. They are also involved in setting up new branches and groups in areas where there is little support for people with motor neurone disease.

Equipment Loan - a limited range of equipment is available where not obtainable from statutory services. Requires a written referral from the relevant health or social care professional

Financial Support - towards items not available from statutory services. Requires referral from relevant health or social care professional

Northamptonshire Local Branch

Open Meetings Local support from people in the area who are familiar with the affects of MND. The branch holds bi-monthly meetings for anyone with, or interested in, MND at St Matthews Church Parish Centre. (Contact details on next page).

Association Visitors (AVs) are volunteers who offer advice and support to anyone affected by MND, either face to face, via telephone or email. Please contact your RCDA on the number above for more information.

Social Gatherings are occasional opportunities for people affected by MND to come together informally in a safe, friendly environment. Transport can be arranged if necessary.

Lunchtime Support Group is another opportunity to meet informally. It is usually held on the 1st Wednesday of every month at the restaurant in the Garden Centre, Newport Pagnell Road, Wootton, Northampton NN4 6HP. There is no need to book – just come along but, if possible, please arrive by 11.45 so we can take your order. Free for anyone with MND and their carer.

NORTHAMPTONSHIRE BRANCH CONTACTS

Patron Rev Dr John Smith

Chair	Kate Inchley	01933 667616	inchleyk@gmail.com
Vice Chair	Robert Nixon	01933 229602	robchnixon@talktalk.net
Secretary	Gerry Skipper-byer	01536 723304 07861 610323	gedda1064@gmail.com
Treasurer	Colin Byer	07779 225760	colin.byer@yahoo.co.uk
Branch Contact	Kate Inchley	01933 667616	inchleyk@gmail.com
Newsletter	Chris Hull		chull1@waitrose.com
Website	Derrick Peasland	01604 454870	dellpea@ntlworld.com

Association Volunteers (AVs)

Joan Randell, William Standerwick, Angela West, Margaret Robinson, Joanne Burkimsher and Annette Liddon

Committee Members

Kevin White, Derrick Peasland, Jackie Atkins, Dave Atkins, Maureen Sanders, Christine Hull, Priscilla Davies, Ali Buttress and Sally Wilkins

E-mail address: enquiries@mndnorthants.org.uk
Website: www.mndnorthants.org.uk

Registered Office:
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10-15 Notre Dame Mews
Northampton NN1 2BG

Registered charity number – 294354