mnda motor neurone disease association

Newsletter

Northamptonshire Branch

MARCH 2018

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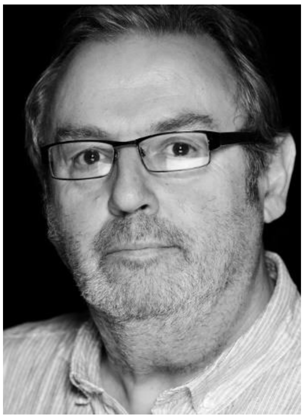
Welcome to the Spring issue of our local newsletter

CHALLENGES



Burton Latimer woman's appeal for challenge ideas in memory of her husband

Jan Warren, whose husband died from motor neurone disease, has embarked on a year of challenges in his memory. David Warren died just 20 weeks after being diagnosed with MND. Jan is hoping 2018 will be a year to remember as she kick-starts 12 months of adventures and feats to raise money for charity.

So far, Mrs Warren has been challenged to complete 10 random acts of kindness, take part in a 'cocktail crawl' of Burton Latimer, hold a bake sale, complete a walk from Burton Latimer to Rushden Lakes, brave a hose-down challenge at a fire station and volunteer at two hospices supporting MND patients. She is appealing for more ideas for challenges to raise as much money as she can for the Motor Neurone Disease Association.

Mrs Warren was made a trustee of the charity shortly after the death of her husband. The couple moved from London to Burton Latimer when they retired. However, their dreams for retirement came crashing down when Mr Warren was diagnosed with MND in May 2015. Mrs Warren said: "In February 2014, David and I moved to our beautiful new house in Burton Latimer – the retirement home we had always dreamed of while working so hard in London for 25 years. "Sadly on May 1, 2015, David was diagnosed with MND and lost his life to this insidious disease just 20 weeks later. "My journey into MND with David began when he was diagnosed. "Although his journey ended on September 9, mine did not. "I felt I should not only honour the bravery and stoicism he displayed whilst enduring the disease, but also become more deeply involved in helping to find the cause and cure. "I became a trustee for the charity 12 months after David's death in order to help using my skills in accountancy and as his carer to try to help future sufferers and find a cure."

Mrs Warren's daughter Janaya, who lives in America, is also taking part in a year of challenges. Mrs Warren is appealing for people to make a donation once she has completed a challenge set by them. She added: "The MND Association helps not only those stricken but their family, friends and carers in every aspect of the journey into the disease and after. "This vicious disease strikes without acknowledging age, gender or the hopes and dreams of the sufferer and their family. No cause has as yet been found and only through research will we find a cure."

To submit ideas for 'Challenge Jan' or to donate to Mrs Warren's fundraising visit www.justgiving.com/fundraising/janwarren184.

Published: Friday 02 February 2018
Read more at: https://www.northantstelegraph.co.uk/news/burton-latimer-woman-s-appeal-for-challenge-ideas-in-memory-of-husband-1-8360387

Jay Lucas' Move the World Challenge Update

Jay and his team are 'circumnavigating' the world for Motor Neurone Disease Association because 10 years ago, his father was diagnosed with MND**.** Jay says **"**Sadly, for my Pops, a little over a year after his formal diagnosis, he died. Over the course of a year, from Sat 6th May 2017 to Sat 5th May 2018, we aim to circumnavigate the equivalent of the Earth's diameter by Running, Swimming, Rowing, Cycling, Jogging and Walking those Extra Miles...

Starting in Northampton, England, we will each 'donate' miles into the pot & hopefully complete the full 24,881 miles* in just 365 days - moving round the world to raise invaluable funds to help those who may not be able to and also support further research into this horrendous, indiscriminating illness.

*The circumference of the Earth at the Equator is 24,901.6 miles but, if you measure it through the North & South Poles, it is slightly shorter at only 24,859.8 miles. Therefore an average of the 2 distances is 24,881 (to the nearest mile)."

The challenge is on the way home with less than 6,500 miles to go, and is currently crossing the Atlantic from New York, en route to Cape Verde with 12 weeks to complete the journey ending in Abington Park Northampton on Saturday May 5th 2018.

To follow the challenge go to the link www.mndworld.co.uk or to donate www.justgiving.com/mndworld

FORTHCOMING EVENTS

MND Association Northants Branch Annual General Meeting AGM
Sunday April 8th 2018 2.30pm --- 5pm
at St Matthews Church Parish Centre, 27a The Drive, Northampton NN1 4RY
The annual Financial Statement is presented and election of officers and committee takes place. Our speaker is Oli Hiscoe MND Association Fundraising .
If there is anyone you would like to nominate for the committee please fill in the attached nomination form, you must get their permission before nominating them, send the completed form to the branch secretary:-
Mrs Gerry Skipper-Byer, 16 Fineshade Close, Barton Seagrave, Kettering, NN15 6SL

Bag Packing at Morrison's
Paula Solomon has been able to arrange bag packing at Morrison's Kettering Road Northampton on **Saturday May 12th 9am – 2pm and Sunday May 13th 10am --- 2pm .** We will need lots of help with this to cover maximum 12 tills both days. If you have any time at all please let Paula or myself know. I know some of you already have done so,, we will sort out times /rota once we know how many are available

Kate Inchley

THREE DIANAS

In October 2008, four years before my husband, Roger Smith, was diagnosed with MND, we took our first cruise together and we travelled on the QE2 on her final Mediterranean voyage, following which she departed to Dubai to be turned into a high-class hotel.

In amongst the paperwork we found in our cabin was an alphabetical list of fellow passengers and I saw that my name, Diana Smith, was listed twice. I assumed it was an error and someone had duplicated my name by mistake. However, the next day we received a call from the Purser's office, advising that Mrs Diana Smith, from New York, would like to speak to us, if we were willing for her to be given our Stateroom number. We confirmed that that would be ok and, a bit later in the day, our phone rang and the American Diana Smith was on the other end of the line. We agreed to meet and that evening Roger and I met with her and her husband, Robert. We had a drink together and exchanged addresses. We met up a couple more times on the cruise but didn't know whether we'd ever see either of them again. We did all keep in touch, however, and I let them know when Roger was ill and then when he died in March 2016.

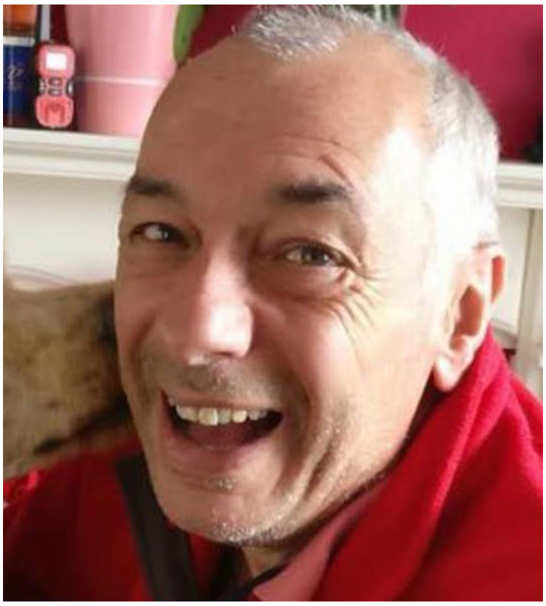
Early last year, my friend Ann asked if I would like to go on holiday with her in November, as it would be her 70th birthday and she wanted to go somewhere special to celebrate. After tossing place names here and there we finally decided on a trip to New York, where neither of us had been before. Needless to say, I told Diana and Robert about our proposed visit and American Diana offered to spend a day with us showing us various bits of New York, including the Metropolitan Museum of Art and Tiffany's Store! She also told me that she knew a lady, who worked at Tiffany's, whose name is Diana Smith. It was agreed that the three of us would try and meet when Ann and I were in New York, and we were able to do so.

This photo shows the three of us, with me on the right, Diana from Tiffany's in the middle and American Diana on the left. New York is a long way to go to meet two other namesakes, but it was well worth the effort (and money!).

Diana
16 Jan 2018

A TRIBUTE

David Solomon



It is with sadness and regret we inform you that David Solomon lost his battle with MND on Sunday February 11th 2018.

Since being diagnosed with this debilitating disease Dave has been an inspiration to everyone in the branch, staff at David Niven House and all who knew him, bearing this disease with dignity. He lived life to the fullness of his capability always ready to have a laugh and joke.

He appeared in the MND Association national ”Eyes Have It” campaign last year and was always ready to share his story with those who would listen.

Dave and Paula his wife, were runners in Northampton Running Club raising money with Marathons and many other running events. When MND robbed Dave of his legs that didn’t stop him, along with Paula and friends from the club he took part in his wheelchair - still raising money and awareness.

Dave will be missed very much by so many people especially those of us who attend the monthly Drop–ins, but his enthusiasm will stay with us all a very long time.

We shall never forget his favourite song “Always Look On The Bright Side of Life” because that’s what he did - however he was feeling.

Our thoughts are with Paula, Chloe and Daniel at this sad time

Kate Inchley
Chair/Branch Contact Northants Branch

Christmas Buffet Lunch 2017

As you may be aware, our Christmas Buffet Lunch get together didn't happen, due to the inclement weather. We had snow !!! We were very sorry to cancel but had no other choice., people would have found it impossible to get there and it was cold !!!

We missed everyone, it is always well supported and gives us a chance to relax together, enjoy good food and entertainment, spend social time and chat.

We were grateful to Morrison's Wellingborough who kindly said they could sell the food prepared for us, and also gave back the £20 deposit. Our thanks to St Matthews Church Parish Office for not charging for the room and kitchen hire. Carol and Helen, our friends who were doing the catering, had the problem of dealing with food already prepared by them, we are very grateful to them for their support. The Christmas cake made by Paul was turned into a celebration cake for his newborn grandson (grandma is Cheryl is OT at Cynthia Spencer Hospice). If you missed seeing everyone please come along to one of our support meetings, dates are listed below and on the website or come along to the Northants Branch AGM on Sunday April 8th 2018 .

DATES FOR YOUR DIARY

Roger Smith Memorial Concert
Saturday March 3rd 2018 11am
St Mary's Church Knox Road Wellingborough NN8 1PX
Music will be played by three resident organists
Cake Sale 10.30am and after the concert (cake donations welcome)
All proceeds from the Cake Sale to Northants Branch MND Association
No admission fee but donations very acceptable
(to be split between St Mary's Church and Northants Branch MND Association)

Drop In Lunch 11.45am --- 2pm
Wednesday March 7th 2018
The Garden Centre Newport Pagnell Road Wootton NN4 6HP

Drop In Lunch 11.45am --- 2pm
Wednesday April 4th 2018
The Garden Centre Newport Pagnell Road Wootton NN4 6HP

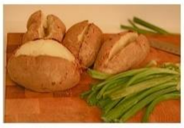
Northants Branch Annual General Meeting AGM
Sunday April 8th 2018 2.30pm --- 5pm
St Matthews Church Parish Centre ,27a The Drive Northampton NN1 4RY
More details to follow . Any nominations for committee contact
Kate Inchley Chair /Branch Contact inchleyk@gmail.com

A Musical Evening with Wollaston Singers
Friday April 20th 2018 7.30pm
The Windmill Club Glassbrook Road Rushden NN10 9RP
Licensed Bar, Raffle
Tickets £5,00 Contact Kate inchleyk@gmail.com 01933 667616
Proceeds to Northants Branch MND Association
Drop In Lunch 11.45am --- 2pm
Wednesday May 2nd 2018
The Garden Centre Newport Pagnell Road Wootton NN4 6HP

DROP-IN LUNCH

YOU ARE WELCOME to join us for an informal lunchtime get together for anyone affected by MND
This is an opportunity to meet and share experiences





Soup, a toasted sandwich, a hot meal 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

DATES FOR 2018

January 3rd
Februry 7th
March 7th
April 4th
May 2nd
June 6th
July 4th
August 1st
September 5th
October 3rd
November 7th
December 5th

SERVICES EXPLAINED

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 – 0808 8026262 - 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.maloey@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

Registered Office: Motor Neurone Disease Association
David Niven House, 10-15 Notre Dame Mews Northampton NN1 2BG
Registered charity number – 294354

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 to share experiences.

It is usually held on the 1st Wednesday of every month at the restaurant in the Garden Centre, (next to Waitrose) Newport Pagnell Road, Wootton, Northampton NN4 6HP. There is no need to book – just come along but, if possible, please arrive by 11.45. Free for anyone with MND and their carer.

NORTHAMPTONSHIRE BRANCH CONTACTS

Patron: 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, Angela West, Margaret Robinson, Annette Liddon and Deborah Bull

Committee Members: Kevin White, Derrick Peasland, Jackie Atkins, Dave Atkins, Maureen Sanders, Priscilla Davies, Ali Buttress, Sally Wilkins¸ Diana Smith and Paula Solomon.

Website: www.mndnorthants.org.uk
Email: enquiries@mndnorthants.org.