

Northamptonshire Branch

September 2018



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Welcome to the autumn edition of our
local branch newsletter

RECENT EVENTS

Buckingham Palace Garden Party

I was very privileged to have my name put forward by the Association to be invited to attend a Buckingham Palace Garden Party.

May 31st was my day. My sister, Jackie Phillips, came with me, as 'my guest'.

Despite storms being forecast that day, it turned out to be a warm, sunny afternoon.

Walking through the main Palace gates and then through the Palace itself was exciting and slightly awe inspiring. The Gardens when we reached them, equally so.



Afternoon tea was served at 3-30pm before the Queen, escorted by Prince William and other members of the Royal Family, emerged from the Palace at precisely 4pm. Following the National Anthem, the Queen, accompanied by the other Royals walked through the Gardens, being introduced and talking to those chosen. We, then, were able walk through the Gardens as we wished.

A delightful experience. Informal within the formality of it all. At 6pm the Queen returned into the Palace, my sister and I back to St Pancras Station !!! A glass of wine while we waited for the train ended such a traditional, memorable, exciting day.

A sincere thank you for such a wonderful experience.

Joan Randell Association Visitor

Annual Conference and AGM Saturday July 14th 2018

The Conference commenced with registration and networking.

Chair of Trustees, Alun Owen, welcomed everyone and made introductions.

Sally Light C.E.O. MND Association reflected on the previous year 2017.

When 1274 researchers from 36 countries attended the Symposium in Boston USA She also highlighted that the 21st Care Centre opened in Norfolk and the 22nd Care Centre would be opening shortly in Stoke-on-Trent

Nick Goldup Director of Care Development presented Our Approach to Improving Care Support - to complement the care services and aim to keep people as well as possible. Nick went on to say

1. What are we trying to achieve,
2. What does good care look like
3. Where have we made a difference
4. What challenges do we face

Three Workshops followed a coffee break
Care –Shaping MND Support
MND Connect - Helpline and Support Services
Legacies - Every conversation Counts

The AGM of the MND Association followed lunch

The handover from the retiring Chair of Trustees, Alun Owen, handing over to Richard Coleman the new Chair

The Guest Speaker was Professor Martin Turner presenting a talk on The Biomarker Challenge

The afternoon ended at 3.45pm

For more information on the 33rd Annual Conference and AGM visit the MND website at www.mndassociation.org

Kate Inchley – Chair Northamptonshire branch



Memorial Concert

Earlier this year, in March, it was the second anniversary of my late husband, Roger's, death. The Vicar of St Mary's, Wellingborough, where Roger used to be one of the organists, agreed that we could put on another memorial concert and the other organists, Lee Dunleavy, Mark Raban and Christopher Colby, said they would put together a programme of music, and I decided to organise a stall to sell cakes and enhance the money raised. The date was set for Saturday, 3rd March and everything was in hand.

However.....

The Beast from the East had other plans. He sent snow to Wellingborough on the 2nd March, which meant the concert had to be cancelled, primarily for safety reasons. But, what was I to do with the cakes I and several other very kind people had made. There was nothing for it but to sell them at the church after the Sunday service...and the outcome of that was that I raised more than £70.

Plans had to be made to re-arrange the concert and it was agreed that, because of commitments previously made by one or other of us, it couldn't be done until 14th July, which seemed a long time away. Of course, it wasn't, and the time soon passed. Before I knew it, I had to start baking more cakes and inveigle my friends into doing the same. Once again, they came up trumps and on the day of the concert the cake stall was groaning under the weight.

The weather on 14th July couldn't have been more different to that of 3rd March – instead of snow we had a heatwave. Nevertheless, although it was sweltering in the organ loft at St Mary's, Lee, Mark and Christopher did Roger's memory proud with their playing of pieces by Leon Boellman, Sir Edward Elgar, Frederic Chopin and even an arrangement of The Beatles song "All You Need is Love" by Paul Ayres, to name but a few. There were more than 100 people in the audience so the applause was terrific, and very well deserved.

We served sparkling wine, as well as apple and orange juice, after the concert and people were encouraged to buy raffle tickets in addition to the cakes. Including the money I'd saved from the earlier cake sale, I was able to give a cheque for £647.15 to Kate Inchley for the Northampton Branch of the MNDA.

My grateful – and HUGE – thanks to everyone who helped to make this possible. I just wish I'd remembered to take a photo of the cake stall.....maybe next time!

Diana Smith



On **Saturday July 21st**, Kate, Peter, Jackie, Dave, Kevin, Shirley and Walt ran a tombola and bric a brac stall at St. Mathews Church rooms. There was also a car boot outside, Despite the heat it was well supported and we

raised £123. 06p.

It was an enjoyable morning. Many thanks to Walt for sponsoring the Tables.

Jackie Atkins

FUTURE EVENTS

Apart from the usual Drop-ins at the Garden Centre on **the first Wednesday of every month** we have the following events.

The Walk to D'feet will take place **on Sunday September 16th** at Abington Park Northampton start time 2pm Full details are on page 8

Open Meeting Sunday October 14th 2018 2.30pm--- 4.30pm at St Matthews Church Parish Centre Northampton NN1 4RY
This will be a social afternoon with Christmas Cards Sales

Saturday October 20th Coffee Morning at
7, Francis Dickens Close Wollaston NN29 7RH 10 am 12.30pm
Cake Stall, Preserves, Christmas Cards ,and Raffle
All welcome please come and join us

Sunday December 9th 2018 1.30pm --- 5pm
Christmas Party Buffet Lunch with Entertainment .
We are trusting this will go ahead without SNOW this year
Please check the website for more details nearer the time

INFORMATION

TALARMADE Head-up Collar

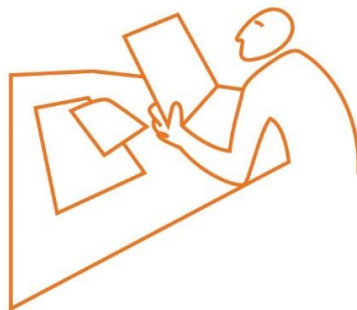


Evidence based collar for neck weakness. Originally developed for Motor Neurone Disease patients the collar can offer a functional alternative for many conditions that require support for the head and neck. These were available to look at and try on at the MNDA AGM and Conference. They do need to be fitted properly to get the maximum support needed. To find more information details are as follows

Email info@TalarMade.com

Website www.TalarMade.com

Could you join the online Information Review Group?



The association are currently looking for people affected by MND, to volunteer to join their online Information Review Group.

The group look through drafts of MND Association information, then provide anonymous feedback to help shape publications before publishing. This helps ensure our information resources are fit for purpose for people affected by MND.

Members can choose the type and number of projects they take on. If you know of someone who may wish to help, please ask them to get in contact

by email volunteering@mndassociation.org or calling 01604 611797.



Every six months, our branch treasurer, Colin Byer, will provide a summary of branch income and expenditure of funds

6 months to 30th June 2018

Income	£ 6,521
Expenditure (inc 2017 Annual Transfer £4,955)	£16,274
Bank balance at 30 th June 2018	£ 4,572
General funds balance at 30 th June	£ 2,902
Restricted funds balance at 30 th June	£ 1,670
Total fund balances at 30 th June	£ 4,572

Our expenditure in the last six months in support of people affected by MND included the following items:

Equipment: Riser/recliner chair, BioBidets, mobile arm supports, slings, toilet lift, contributions to stairlift installs

Grants: Holiday grant, Carers grant

Financial support: Quality of Life support, transport costs, hydrotherapy costs

In addition, we continued to fund the travel costs of our wonderful Association Visitors and the costs of the popular Drop-in meetings.

The Branch relies on fundraising and voluntary donations for all of its income, and we are grateful to all who have supported us in this way over the last six months. Your efforts and generosity are truly appreciated – thank you.

Colin Byer



ABINGTON PARK WALK NORTHAMPTON

16th SEPTEMBER 2018

DISTANCE: 3 MILES

Walk starts at 2.00pm (registration from 1.30pm)

To raise funds for the MND Association &
the Northants Branch.

Please bring a picnic so we can get together to
celebrate at the end of the walk!

We'd love donations to -

<https://www.justgiving.com/walk2dfeetmnd>

To register and find out more contact your Team
Leader:

Name: Jan Warren

Email: jan.warren@mndassociation.org

Phone: 07889 137671

Motor Neurone Disease

- Kills six people every day in the UK
- Leaves people unable to walk, talk or feed themselves
- Is fatal with no known cure
- Affects up to 5,000 adults in the UK at any one time

The MND Association

- Provides information and support for people with MND and their families
- Funds vital research into causes, treatments and a cure for MND
- Relies on voluntary donations



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.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

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, Jackie Atkins, Dave Atkins, Maureen Sanders, Priscilla Davies, Ali Buttress, Sally Wilkins and Diana Smith

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