

Newsletter

Northamptonshire Branch

JUNE 2016













OUT and ABOUT FUNDRAISING

WAITROSE Green Box Community Matters



During the month of February Northants Branch were fortunate to be part of the Waitrose Green Box Project in Towcester

£628 was raised

Thanks to all who supported us

SEVENS Pub and Restaurant

On April 16th at very short notice Sharon and Sandy went to the **SEVENS PUB** on the Weedon Road for a collection. We had been invited by the Landlord /Manager Dan Coles for the local derby between Northampton Saints and Leicester Tigers end of season rugby match. The pub being opposite Franklins Gardens, there were lots of supporters of both teams. Peter and Kate joined Sandy and Sharon a bit later. The collection raised £248 36. A letter of thanks was sent to Dan, our thanks to all who contributed and to Sharon and Sandy for stepping in just a few days before.



CONCERT Windmill Club Rushden

A very successful concert took place at the Windmill Club Rushden on Friday April 29thwhen the Wollaston Singers sang numbers from their recent local show including medleys from Les Miserable, Mamma Mia and many popular songs. Mario Wolfgang was a great hit, playing his acoustic guitar and singing songs some he had written



himself. Mario had recently appeared on BBC1 The Voice. An amazing raffle helped boost the funds and £674 was raised on the night. Our thanks to all who took part, those who contributed raffle prizes and to all who came to make the evening the success it was.

CELL at The Castle Theatre Wellingborough

The Company Cell portrayed the story of Ted diagnosed with MND. Ted goes on a trip of a life time with his pet fish. He rushes from the markets of Lille to the romance of Venice. Heart warming and humorous, it features puppetry, physical theatre and original score to tell the story of one man's final adventure. Peter and Rob set up in the foyer with display leaflets and collecting buckets. Staff from David Niven House (MND Association Head Office) attended the show which was held in the Studio the smaller of the two theatres holding 80 people. A collection raised £52.56.





Six Go Singing

Last December, Jay Lucas and Six Go Singing gave their sixth Christmas Concert in Roade.

They performed many Christmas favourites and, for the second year, were joined by Jinx – another group with their roots in Roade, who entertained everyone with their fine acapella singing.

Almost seventy attended and a good night was had by all. Ticket sales were the best ever and, combined with takings from a busy refreshment counter and from a very good raffle, the evening raised over £500 for the local branch of the MND Association.

Six Go Singing and some musical friends will be back in Roade next Christmas and would love to see you!

ANNUAL GENERAL MEETING

Twenty four people attended the recent AGM of Northants Branch held on Sunday April 10th.

Usual business took place, the Chair gave her annual report highlighting events through the year and thanking committee members, members, their families and friends for all the support during 2015.

The Finance report by the treasurer was followed by election of officers and branch committee.

Chair Kate Inchley

Vice Chair Rob Nixon

Treasurer Colin Byer

Secretary Gerry Skipper-Byer

Web-Master Derrick Peasland

Committee Members Dave Atkins, Jackie Atkins, Ali Buttress, Priscilla Davies, Maureen Sanders, Kevin White, Sally Wilkins.

Chris Hull stood down from the committee but still continues as Newsletter Editor, it happened to be Chris's birthday and she was given a card and flowers, thanked for her work on the committee and we are grateful she remains involved.

There were no Long Service Medals this year. Our guest speakers were Diana Smith, member, and Scott Maloney, RCDA Central Midlands.



Diana presented a very informative and interesting talk with photographs of her recent cruise visiting many places in the Caribbean and telling us about customs and cultures in the different islandScott Introduced himself and explained he had only been in his post as Regional Care Development Advisor and Coordinator for the Association Visitors at the association for a few months and previously with MND Connect.

The afternoon ended with tea and cakes.



Kate Inchley

RAISING AWARENESS



Silence Speaks is more than just a sponsored silence, it's about finding other ways to communicate. Whether you are taking on the MND Association challenge on your own, getting your workplace involved or taking part with friends and family, we have all the tools and information you need to help you – or you can visit the volunteer

zone on the MND Association website where you can download lots of hints and tips to help complete your challenge.

Supporting Silence speaks will make a huge difference to people living with MND. We know that more than 80% of people living with MND experience communication difficulties, and for many this can be the hardest part of the disease. So, why not sign up today and 'lose your voice to help others be heard'.

We also have a NEW teacher and youth leader pack for 2016 with lots of ideas and useful resources to engage young people in the event which we would be happy to send to any schools, colleges, universities or youth groups you may have contact with.

To take part simply visit <u>www.mndassociation.org/silencespeaks</u> or to find out more and get started make contact with your Regional Fundraiser Sharon King - <u>Sharon.king@mndassociation.org</u>.

BENEFITS ENTITLEMENT ADVICE





Many people with MND miss out on benefits they should be claiming, simply because they do not have the right information or cannot deal with the complex processes and lengthy claim forms involved.

The MND Association is about to launch a new Welfare Benefits Advice Project across the six counties of the East Midlands (which includes Northamptonshire) and Oxfordshire, Buckinghamshire, Gloucestershire and Berkshire. The project is designed to provide people with MND and their carers access to specialist benefits advice over the telephone and also provide support with completing claim forms for Personal Independence Payment and Attendance Allowance. Advice can also be offered by text, email or Skype if this is preferred.

The telephone advice will be provided by Leicester Community Advice and Law Service and we have trained five volunteer Benefits Navigators to undertake home visits and help with the completion of claim forms. Leicester CALS holds the Advice Quality Standard accreditation so we know the advice provided will be accurate and up to date.

It is important to get advice after diagnosis, but also as circumstances change – the service can be accessed whenever needed.

The service will offer full benefit checks to identify any unclaimed entitlement and any on-going support necessary such as representation at appeal hearings if necessary.

If you would like advice please contact:

Dawn Eckersley

Welfare Benefits Project Manager

07872 161674 (phone/text)

dawn.eckersley@mndassociation.org

NATIONAL CARERS WEEK

As some of you may be aware, it is Carers Week starting 6th June- 12th June 2016.

If you would like to attend one of the local events or would like more information please call 01933 677837 or go to http://www.northamptonshire-carers.org/carers-week-2016

HOLIDAY VILLA PORTUGAL

I thought my days of travelling abroad were over but knew of someone who had been to a villa in Portugal which was adapted for wheelchair users. When I mentioned this to a friend, she immediately said we could manage to do that and suggested her step Dad could come too. Before I knew it, the villa and flights were booked for the 1st May and my husband was looking forward to some respite, staying at home to go fishing.

We booked Special Assistance at the airports which made the process of checking in and boarding the plane easy. We were met at Faro airport and driven to the villa which is set on a hill overlooking the Algarve coast. It has a large garden, a pool with a hoist, ramps to the terraces and inside it is easy to access all areas. The villa sleeps seven adults plus two babies/toddlers, there is a hoist in one room with an ensuite room with a level entry shower area with commode\shower chair, and raised toilet seat.

The owner is English, very helpful and lives nearby. If required, she can arrange for any extra equipment to be hired and delivered. The use of a WAV (Wheelchair Accessible Vehicle) is included in the villa cost and meant we could go out every day.

My main concerns about the flights were unfounded and my other worry was finding accessible toilets if we went out – again no problem! Because it went so well and was far easier than I expected, I wanted to share the experience and, maybe just maybe we could go again!!

Details about Luz do Sol Villa are on www.algarve-vacations.com with beautiful photos and good information.

Chris Hull chull1@waitrose.com

FORTHCOMING EVENTS

Drop-In Lunch Wednesday June 1st 11.45am --- 2pm

Wyevale Garden Centre Wootton Northampton

Open Meeting Sunday June 12th 2.30pm --- 4.30pm

St Matthews Church Parish Centre

27a The Drive Northampton NN1 4RY

This meeting will have a Royal Flavour as the nation celebrates

Queen Elizabeth's 90th birthday

Northants Branch Charity Sponsored Walk to D'feet 10am --- 2pm

Irchester Country Park (see page 8 for more details)

Drop-In Lunch Wednesday July 6th 11.45am --- 2pm

Wyevale Garden Centre Wootton Northampton

We have NO Open Meeting in August

Quiz Night Saturday November 12th

At The Obelisk Centre, Kingsthorpe, Northampton



Walk to D'feet Saturday June 18th 2016 Venue Irchester Country Park

Registration from 9.30am

Walk to commence approximately 10am

There are three different trails

Yellow Trail ½ mile very wheelchair friendly with fully hard_surfaces.

Red Trail 1 & 1/3 mile not so wheelchair friendly part hard surface, part soft track, some short grass can be done with strong people to help over tree roots etc.

Black Trail 2 miles Roughly the same as red but longer maybe more obstacles.

Choose one or do all three.

Contact Kate 01933 667616 email <u>inchleyk@gmail.com</u> for sponsor and registration forms and further information.

Please come we need your support. Bring your own picnic lunch many lovely areas to sit.

The park is dog friendly, leads may be needed in some areas

Café and toilets.

There is a charge of £3.00 for car parking.

Blue Badge holder parking is available near to accessible toilets (pay and display charge applies)

Take a look at the park on www.northamptonshire.gov.uk Irchester Country Park if you do not know it.

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

qedda1064@gmail.com

Treasurer: Colin Byer 07779 225760

colin.byer@yahoo.co.uk

Branch Contact: Kate Inchley 01933 667616

inchleyk@gmail.com

Newsletter: Chris Hull <u>chull1@waitrose.com</u>

Website: Derrick Peasland 01604 454870

dellpea@ntlworld.com

Association Volunteers (AVs): Joan Randell, William Standerwick, Angela West, Margaret Robinson and Annette Liddon

Committee Members: Kevin White, Derrick Peasland, Jackie Atkins, Dave Atkins, Maureen Sanders, Priscilla Davies, Ali Buttress and Sally Wilkins

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