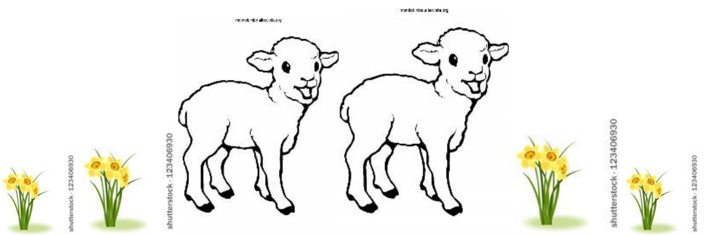
mnda
motor neurone disease
association

Newsletter

Northamptonshire Branch

MARCH 2016



OUT AND ABOUT

On Saturday November 28th, Kate, Peter, Dave and Jackie had a table at a sale held in Wollaston Village Hall. We ran a tombola, sold knitted items and some bric a brac. It was extremely well supported, especially as Santa was there. There was a lovely festive atmosphere. We raised £122.

Donation from ASDA customers

On December 8th Peter and Kate went to ASDA in Far Cotton Northampton to receive a cheque for £200. This donation came from the Community Matters Green Boxes. A kind person, unknown to us, had nominated the branch and our grateful thanks go to that person and to ASDA in Far Cotton Northampton.

Christmas Party Buffet Lunch

Another successful Christmas celebration was held on Sunday December 13th 2015 at our usual venue, St Michael's Church Room in Northampton. Over fifty people attended and enjoyed a great lunch, which this year we organised ourselves, helped by the very capable hands of Carol and Helen who are friends of Vice Chair Rob and we extend our thanks to them. The raffle raised a wonderful £184.00.

Kevin, a committee member, sings with Open Stage Choir who provided a very enjoyable half hour of entertainment especially from the pianist. I express my thanks to all members, committee members and friends who helped once again to make the afternoon so enjoyable.

Kate Inchley Branch Chair

SAINTS BUCKET SHAKE

This the one and only photo we took on a very wet & windy night! We raised £432.34 so it was definitely worthwhile despite the weather and the Saints losing! Myself, another committee member, Kevin, and my family scattered ourselves around the Saints ground before the match to collect as much as we could.

The reason I wanted to do the bucket shake at the Saints ....

Dad was a massive Northampton Saints fan, and season ticket holder, for many years. He would walk from Kingsthorpe to the ground on match day, stopping off for a pint or two on the way. Even in his latter stages of his MND battle he would still attend the matches. After diagnosis he was lucky to meet some of the players at a dinner function and we were given a signed shirt. Our family continue to support the Saints, three generations of the family being season ticket holders and sitting where Dad sat.

Ali Buttress

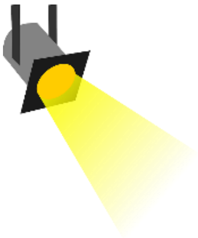
The Pig That Squealed by Mike Hollowell

Mike Hollowell, was born and grew up in Northamptonshire. Mike has written a book, *The Pig that Squealed*, which is a collection of thoughts and reminiscences of his life in rural Northamptonshire from 1935 until the mid -1950s, obviously covering the years throughout WW II and after.

Mike is donating £2 of every book sold to MND Northants Branch funds. At the Lunch Drop-in on February 3rd Mike presented me with a cheque to the value £600. We are extremely grateful to Mike and pleased his book sales are going well. The book price is £7.00, should you wish to purchase one please contact me on 01933 667616 or email Inchleyk@gmail.com

Kate Inchley

SPOTLIGHTS



Symposium Blog –First Impressions

Rachel Boothman, Head of Education and Information, MND Association

I was fortunate enough to attend the 26th International Symposium on MND which took place in Orlando, Florida in December.....here are some reflections from a first timer. The Symposium is an annual event, organised the by MND Association, which brings together more than 800 researchers, scientists and clinicians from across the globe.

My Hopes

Having recently moved into a new education role at the MND Association, I was armed with a ‘to do’ list of networking, horizon scanning for developments in respiratory/nutritional care and relaying learning via our online professionals forum. I was also tasked with the honour of helping to judge the clinical poster prize alongside two renowned neurologists from the USA and Australia.

Every year, we hear about the fantastic collaborations, projects and new discoveries that emerge from this annual gathering, but I didn’t wholly understand the enormity and significance of this international community until experiencing it first hand.

It is a challenge to articulate the scale and breadth of work going on across a whole raft of subject areas, which range from complex clinical trials to very simple changes in care pathways which can make a significant difference to those living with and affected by MND.

Networking

Delegates heard about the results of collaborations formed at the last year’s Symposium and new links were made this year, which will no doubt prevent duplication of work. I was able to hook up with my counterpart at the ALS Association in the USA and we have already made contact via email since arriving home! There were also opportunities to share ideas and resources around developing services for children and young people affected by MND. If that's not enough, I learned how the 'tweet' and share information on social media!

The Poster Prize

The poster exhibition hall alone was the size of an aircraft hanger, half of which was dedicated to more than 300 poster displays from all corners of the globe.

The objectives of the poster prize are three fold: to increase the profile of the poster sessions; to recognise the quality of the work presented and to reward presenters for outstanding work. Two final prizes were awarded, one selected from the clinical and scientific programmes, respectively. The prize itself is a certificate and a medal.

Ed Kasarskis from the USA and Matthew Kiernan from Australia joined me on the judging panel and delegates were allocated ten minutes to present their posters and answer questions. We were delighted to award the prize for the clinical poster to Dr Rebecca (Becky) Broad from the University of Sussex in the UK. Her poster "Neurite Orientation Dispersion and Density Imaging (NODDI), was in the Imaging and Electrophysiology theme and demonstrated microstructural changes association with MND.

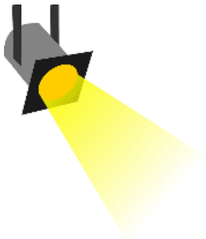
Sessions

For me, the sessions which resonated most were those on cognitive change (assessment and management) and the impact of strain on family/informal carers. It was great to hear about work underway in Cambridge, UK which considers the impact of cognitive change on carers and that guidance is being drafted which will provide non-pharmacological strategies and tools to help manage this.

……and finally

The phenomenal energy, commitment and drive to find new management techniques, treatments and eventually a cure for MND, was evident throughout the Symposium and I heard several delegates state 'it was the best yet'. If I had to use three words to surmise my experience, I would quote my tweet from the final day – inspiring, humbling and hopeful!

Rachel Boothman



MND CONNECT

I am Angela one of the AVs (Association Visitors) I am also a volunteer for MND Connect manning the evening helpline on a rota basis with other volunteers.

I thought it might help if I try to explain how this works.

MND Connect is a nationwide service offering help and advice as well as practical and emotional support to people living with MND, their family, friends and carers. The main purpose is to be a listening ear in times of stress, confusion and upset.

Calls come in from all over Britain but we are able to liaise with local support networks. As evening volunteers we haven't always got access to the information that we might need (as we operate from our homes) but I will always offer to ring the day team the next day if there is a need for follow up. This has to be done with the consent of the person living with MND and the caller.

Just an empathetic chat over the phone can often ease a difficult situation.

I feel this is a vital service and can be a comfort for a person living with MND, their families and carers.

I would encourage all affected by MND to keep the MND Connect phone number to hand if things become difficult.

Personally I have learned (and continue to learn) how MND affects many people’s lives. My role on the helpline is always challenging but I feel worthwhile.

Contact MND Connect Helpline between 9am to 5pm and 7pm to 10.30pm Monday to Friday

on 0808 802 6262 or email mndconnect@mndassociation.org

FORTHCOMING EVENTS

The Christine Harper

Black Tie Ball

IN AID OF MOTOR NEURONE DISEASE

Sponsored by L Harper Scaffolding Ltd

Saturday 5th March 2016

At the Hilton Hotel Northampton

6.30pm - Carriages 1.00am

Pimms on arrival, 3 course meal,
live music by Roy Leslie and disco

Guest speaker ex Arsenal, QPR,
Northampton Town Goalkeeper Lee Harper

Charity auction - Luxury raffle

Heads and tails sponsored by the
Hair Pavilion where
you can enjoy 25% off with your ticket

Tickets £39.50

Call Diana 07903 331738
or Lee 07515 555083

In Memory of
Christine
Harper

mnda
motor neurone disease
association

Contact inchleyk@gmail.com or sharonking@mndassociation.org
for more information

Lunch Meeting
Wednesday March 2nd 12 midday – 2pm
Northampton Garden Centre Wootton NN4 6HP

Lunch Meeting
Wednesday April 6th 12 midday - 2pm
Northampton Garden Centre Wootton NN4 6HP

Northants Branch Annual General Meeting
Sunday April 10th 2016 2.30pm --- 5pm
St Matthews Church Parish Centre
We are accepting nominations for the committee. Should you wish to nominate someone for the committee please get their permission first then fill in the enclosed nomination form and send to our secretary

Mrs Gerry Skipper – Byer
16 Fineshade Close
Barton Seagrave
Kettering
Northants NN15 6SL

Nominations should reach us before March 24th 2016

Musical Evening by Wollaston Singers
Friday April 29th 2016 7.30pm at
The Windmill Club
Glassbrook Road
Rushden
Northants NN10 9RP

Tickets £5.00 will be available from end of February
Licensed Bar and Raffle
Contact Kate 01933 667616 or 07786 686 177
inchleyk@gmail.com

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 – 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

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

Registered charity number – 294354