

Northamptonshire Branch



Newsletter

**JUNE 2018**



**Welcome**

**to the Summer issue of our local newsletter**

## RECENT EVENTS

### Northants Branch AGM Sunday April 8<sup>th</sup> 2018

Thirty people attended the AGM of the Northants Branch MND Association. We were very pleased that the Mayor and Mayoress of Northampton were able to join us. Our guest speaker was Ollie Hiscoe, a Community Manager from David Niven House (DNH), National Office of the MND Association.



The Chair's report was given and events of the year were highlighted. The Chair thanked the committee, AV's, members, volunteers, staff at DNH, the trustees and all who support us every year. Professor Stephen Hawking was remembered as were our own members and people with MND who have lost their battle this past year. The treasurer presented the annual financial report and this was proposed, seconded and



Branch elections took place, with no resignations of branch officers, these were accepted. Two committee members stood down Paula Solomon and Derrick Peasland, these members were thanked by the Chair and Derrick was presented with an acknowledgement and a signed card for over 25 years' service. A card was also signed for Paula but in her absence this will be forwarded to her.

Our speaker, Ollie, then took the floor and spoke about the importance of fundraising, about getting it right and the significant part that social media plays in fundraising and awareness bringing it to the wider population. There was a time for Q's and A's on any of the presentations.

The committee, AV's and volunteers were thanked by Geoff Hull on behalf of Chris our newsletter Editor for their support and commitment to the Drop-ins at the Northampton Garden Centre. Diana Smith gave the vote of thanks to Ollie Hiscoe and to the Mayor and Mayoress and presented the Mayoress with a plant. Jackie and Dave ran a very successful raffle raising £84. for branch funds. The afternoon ended with tea, and cakes which gave everyone a chance to chat.

Kate Inchley

**The Musical Evening at The Windmill Club Rushden on Friday April 20<sup>th</sup>** raised a total of £271.00. Wollaston Singers entertained us with some contemporary songs, plus some well known favourites such as Sit Down your Rocking the Boat, from Guys and Dolls and a medley from Phantom of the Opera. The Wellingborough Music Centre Trad Jazz Band were tremendous playing tune after tune which everyone knew and enjoyed. Another good raffle was well supported, the bar was open and a great evening was had by all, our grateful thanks to all who came. Kate Inchley

## London Marathon 22<sup>nd</sup> April

Michelle Frost, Events Fundraising Co-ordinator at David Niven House completed a Guinness World Record in MND colours for the fastest Marathon on stilts. She did it in 6 hours 37 minutes 38 seconds!!!

Michelle, who has worked at the MND Association for almost two years, set the record for the fastest marathon on stilts in 2008 when she finished the race in 8 hours 25 minutes.

The record has since been broken and 10 years on, Michelle wants to reclaim it by beating a time of 6 hours 50 minutes. She said:

“ I’m now working for an absolutely amazing and inspiring charity and seen the work our amazing fundraisers do, so decided to ask the events team if I could join #TeamMND for the 2018 London Marathon and try to reclaim my Guinness World Record.”

Michelle has been fundraising by selling hundreds of sweets to staff at the MND Association, organising quiz nights, running sweepstakes, hosting stalls at fun days and fetes with her mum and an auction at a Scout Jamboree which raised an amazing £800. She added:

“I learnt to stilt walk with a team at a Scout Camp, and now teach young people to walk on stilts, but even they think I’m mad to be doing this again.”

Her donation page is <https://www.justgiving.com/fundraising/Michelle-Frost5>



## Move the World Challenge

On Saturday May 6th 2017, the combination of a Crazy Idea and a group of Willing Participants began. The aim was to travel the equivalent of 24,881 miles - the circumference of the Earth - by Running, Walking, Rowing, Cycling, Swimming, Jogging, Dancing & even Fencing, All In Just One Year!



On 23rd April 2018... WE DID IT! With Just Under 2 Weeks To Spare...Between us, this bunch of 40 or so wonderful people, had completed 24,881 miles & Virtually

Circumnavigated The World By Human-Power Alone. All In Just One Year!

With Just Over A Week To Go, We Also Reached The £3,000 Mark In Donations!!

On Saturday May 5th 2018, as many of The Team that could, along with some amazing friends, family and supporters met back where it all began & celebrated by doing a 'Last Mile' together



We're Going To Keep Adding Those Miles... & There May Even Be A New Version, So Stay Tuned...Please Help Us To Keep Adding Those Pounds If You Can & Text 'MTWC99' & Your

Amount To 70070 or you can donate here [www.justgiving.com/mndworld](http://www.justgiving.com/mndworld)

Full details and our achievement can be viewed at [www.mndworld.co.uk](http://www.mndworld.co.uk) #mndmtwc

Jay Lucas

## Milton Keynes Half Marathon in memory of Dave Solomon

On 7<sup>th</sup> May, Michael Aldridge won the half marathon for MNDA in 1 hour 13minutes



## **Tombola May 7th St Mark's Church Whitehills, Northampton**

On Monday May 7th Dave and myself accompanied by Margaret and Derek were at St Marks Church, Whitehills for their annual community fete where we did a tombola and raised £82.60. Many thanks to the minister and church members for the invite, it is the third time at this event and we are always made very welcome It was an enjoyable afternoon.  
Jackie Atkins



## **Morrisons Bucket Collection Saturday/Sunday May 12<sup>th</sup>/13<sup>th</sup> 2018**

Members of the branch took part in a bucket collection at Morrison's Store Kettering Road Northampton. £363.62 was raised on the Saturday. During the five hours we were there many people stopped and chatted about people they knew who had lived with MND, some had still not been aware of the condition. Sunday raised £66.86 Jackie and Dave did a 2 hour collection but were interrupted by a fire alarm. When they got back into the store most people just wanted to collect their trolleys and get out. The total overall was £430.48, we are grateful to the people of Northampton who contributed.  
Kate Inchley

## **FUTURE EVENTS**

### **Family Half Term Fundraising Walk**



Hi, I'm Clare, Learning and Development Officer for the Association. I joined in September 2017 and since then have been mostly focusing on training to do with the changes in data protection. I will also be running the Association Get Connected induction days, available to new staff and volunteers. I am based from home, in Northamptonshire, but cover the whole association area and

so far have travelled from the Isle of Wight up to Northallerton and in-between, with the training sessions about data protection. As a family, myself, my partner Tom and our son Ole (aged 12 years) have been inspired to take on the challenge of walking around the Isle of Wight Coastal Path (68 miles) starting on 27 May in Ventnor to raise

funds. We have already raised £1080 so we have reached our £1000 target but we hope to raise lots more during our week on the island.

We will be staying on the Island with our crew (my parents)! We will be fully funding the trip so all money raised will go to the MND Association.

We will be supported by the local Isle of Wight Branch and are hoping lots of people come and say hi and we will raise lots of awareness about the MND Association.

Follow Clare, Tom and Ole (TOC team) on facebook: @TOCteam2018

Donate at [www.justgiving.com/tocteam2018](http://www.justgiving.com/tocteam2018)

### **Drop In Lunch 11.45am --- 2pm Wednesday June 6th 2018**

The Garden Centre Newport Pagnell Road Wootton NN4 6HP This is an informal get together to meet others affected by MND and share experiences Lunch is free for anyone with MND and a carer.

### **Sunday June 10<sup>th</sup> 2018 Open Meeting 2.30pm --- 4.30pm**

A reminder that we have a speaker at this meeting, Dr. Joanne Inchley, talking about her work in Ghana . This will take place at our usual venue St Matthews Church Parish Centre 27a The Drive Northampton . NN1 4RY

### **World MND Awareness Day 21<sup>st</sup> June**

Following on from their signing of the MND Charter, Northampton Borough Council have offered us a free (!) stall within the One Stop Shop at the Guildhall. I requested 21<sup>st</sup> June as this is World MND Awareness Day and they've agreed.

The stall will run from 10 until 4 and will have general info and resources and should be a good opportunity to spread the word about MND – and *maybe* attract new volunteers..? The One Stop Shop is where people go to sort out lots of things such as Council Tax, Rent etc so should be quite busy. I hope to have a DVD 'Understanding MND' on a loop playing on all the screens as well.

I'm intending to be there for the duration and this is an invitation if anyone wishes to join me for an hour or two?

#### **Scott Maloney**

RCDA for Central Midlands

Motor Neurone Disease Association

Tel: 03453751830 Mobile: 07501682095

[scott.maloney@mndassociation.org](mailto:scott.maloney@mndassociation.org)

## **Drop In Lunch 11.45am --- 2pm Wednesday July 4th 2018**

The Garden Centre Newport Pagnell Road Wootton NN4 6HP This is an informal get together to meet others affected by MND and share experiences Lunch is free for anyone with MND and a carer.

## **Concert of Organ Music Saturday July 14<sup>th</sup> 2018 11am**

The Roger Smith Memorial Concert that was postponed from March because of bad weather will take place on Saturday July 14<sup>th</sup> 2018 at St Mary's Church Knox Road Wellingborough at 11am . There will be a cake stall from 10.30am before the concert and then again after it finishes. There is no charge but donations will be gratefully accepted. The concert donations to be split between the Church and MNDA Northants Branch, the cake sale money will go to the branch .Any donations of cakes to be sold will be welcome .

## **The MND Association AGM and Conference Saturday July 14<sup>th</sup> 2018**

Raddison Blu Hotel East Midlands Airport Castle Donington 9am -- 4.30pm

Always well supported and a great chance to meet with like minded people from other branches, staff and trustees from the Association. Information on this would have been in the post with your latest Thumb Print Magazine .

## **Table Top Sale Saturday July 21<sup>st</sup> 2018 10am --12 midday**

We shall be in attendance at the above Table Top Sale at St Matthews Church Parish Centre with sale of Bric –a Brac and a Tombola. Any donations of suitable tombola prizes and bric-a brac would be gratefully received. Call Kate on 01933 667616 Please come and support us at this event .

## **Drop In Lunch 11.45am --- 2pm Wednesday August 1<sup>st</sup> 2018**

The Garden Centre Newport Pagnell Road Wootton NN4 6HP This is an informal get together to meet others affected by MND and share experiences Lunch is free for anyone with MND and a carer.

## **London City Swim 2018 21 September at 4pm Royal Victoria Docks**

A 500 metre open water swim in the city. Up to 600 swimmers will swim the course in waves, and the fastest from each wave will be invited to take part in a final wave to find the fastest swimmer on the day.

Aiming to raise £200,000 to go towards Project AMBRoSIA. AMBRoSIA (A Multicentre Biomarker Resource Strategy In ALS) is our biggest, research project to date. It could help us understand motor neurone disease better than ever before. It could help develop a faster process for diagnosing the disease and may lead to better targeted treatments.

The registration fee is £25, with a minimum sponsorship of £400. Included in your registration fee is a swimming cap, bath robe and food and drink on the day. Wetsuits will be available to hire for a small fee.

The event is free for people living with MND and one carer – fully inclusive and accessible event and personalised assessments will be done to ensure people living with MND can enter the water in whatever way they're comfortable with and with the help of any necessary flotation devices. The event has kayak marshalls around the course who can help assist people in the water if they need it.

After party takes place after the swim with music and food and drink until 9pm.

We are also looking for volunteers to help assist with the delivery of the event in various different roles throughout the day, from meeting and greeting the swimmers, registration desk, providing them with hot drinks and robes upon exiting the water, and marshalling among others.

For details and further information please visit [www.mndassociation.org/LCS](http://www.mndassociation.org/LCS) or contact Clare Salter, Events Manager at MND association on [clare.salter@mndassociation.org](mailto:clare.salter@mndassociation.org) or 01604 611834

## INFORMATION UPDATE

### New MND Association vlog

The MND Association is developing a new series of vlogs to update people on what's new with their information, introduce the team behind the information provision and give an insight into the work of the Association.

A vlog is like a newsletter, but delivered in video format. Videos can be easier to access for people who have difficulty reading, turning pages or who are low on energy.

Chris Hull, who was involved in the first vlog, is a member of the information team's review group. In the vlog, she shares her experiences of getting involved with information development at the Association. She also shares her way of approaching MND Association information, by seeking it out when it becomes relevant to her.

The first vlog is available to view online now at: [www.mndassociation.org/careinfo](http://www.mndassociation.org/careinfo)

Several vlogs will be produced throughout the year to provide regular updates on new and updated information.

The MND Association is also recruiting for new members to join their review group. The group reviews information during development to ensure it is fit for purpose before it is launched. All that is required is that you have an internet connection and access to emails.

If you are interested in joining this group, or for more information, contact: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org) Emily Richardson

## **DONATED SCOOTER**

This Royale mobility scooter has been donated and, at the request of the donor, is now available to pass on, free of charge, to someone with MND

It is 28 " wide

56" high

60" long

Contact: [kevin.hewes@ntlworld.com](mailto:kevin.hewes@ntlworld.com)



## **FOR SALE**

### **WHEELCHAIR ACCESS VEHICLE (WAV)**

**KIA SEDONA 3 CRDi**

**DIESEL AUTOMATIC**

1 previous owner.

Registered 2011 - Mileage 69,000

Silver/Pewter metallic pain. Dove grey leather seats,

Rear wheelchair access conversion 4 seats + wheelchair passenger.

Full length rear door 57" headroom. Fold out ramp. Wheelchair securing system. Climate controlled air conditioning. Alloy wheels. Dual sliding electric doors.

Powered tailgate. Central locking. Electric windows. Heated seats. Electric drivers seat. Cruise control. Privacy glass. Reversing camera. Powered folding mirrors. CD audio system.

**£14,500** ono

Northampton

Contact Mobile 07718 096173

**Please note: All transactions are to be arranged privately between the buyer and seller. The MND Association is not endorsing or affiliated with either of the above items.**

# 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](mailto: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](mailto: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](mailto: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 1<sup>st</sup> 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**

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

**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

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