

Northamptonshire Branch

SEPTEMBER 2015



***Welcome to the Autumn edition of the
Northamptonshire Branch Newsletter***

OUT AND ABOUT

On Thursday June 11th Dave and I went to David Niven House to see C E O Sally Light leave for Oxford on her Bike ride. It was part of a 150 mile round trip over four days being undertaken to raise awareness and funds by visiting the areas with hospitals which feed into the MND Clinic at the John Radcliffe Hospital in Oxford. There was a lovely atmosphere and everyone was looking forward to setting off. It was filmed by Anglia Television and I was interviewed by Sarah Cooper who asked me about my connection with the MND Association. I was a bit nervous but enjoyed it. We feel honoured to have been there.



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Jackie Atkins

Downing Street Charter Presentation and Westminster Reception



On Tuesday June 16th 2015 our C.E.O. Sally Light and members of the MND Association presented our Charter at 10 Downing Street.

33,360 signatures were collected since the induction of the charter three years ago. The purpose of this is to show the new Government the strength of support behind the charter and the importance of working towards achieving the

Charter's vision of the right care, in the right place, at the right time for people with MND and their carers. This was followed by a parliamentary reception for MPs to meet the association's volunteers.

Kate Inchley, Chair /Branch Contact and Rob Nixon, Vice Chair were nominated to attend on behalf of Northants Branch. This gave us an opportunity to meet with local MPs to raise awareness of MND and the association and to attempt to build relationships with new and re-elected MPs. Unfortunately our own local MP was unable to attend but we did meet with David Mackintosh MP from South Northants and Philip Hollobone MP from Kettering. 130 volunteers and 75 parliamentarians attended.

There were three speakers:-

Sally Light, Chief Executive MND Association

David Setters, who is living with MND and a Campaigns Contact

Charlotte Hawkins, who has been affected by MND and is ITV Good Morning Britain Presenter.

This was a very worthwhile and enjoyable experience

Kate Inchley

Walk to D'feet June 27th 2015 Irchester Country Park Northants

Forty people joined us for the Walk to D'feet on Saturday June 27th. It was a lovely sunny day. With the gazebo set up and people registered, we had a group photo before setting off. There were three different trails to take around the park, all different lengths, to walk.



Some did all three trails, the surroundings are beautiful and everyone enjoyed the day. So far we have raised £835, with more to come through people who set up their own Just Giving pages. Many brought a picnic lunch or went to the cafe' for a well deserved lunch.

The Color Run



Trying to get a group of non - runners to run is difficult, to then ask them to raise money for charity is doubly difficult, however, these five ladies did me proud. Not only did they embark on a running training plan, gave up evenings with their families and then on the day be literally covered head to foot in multi-coloured paint powder. Such was their passion for wanting to help people living with MND they took to this challenge with not one murmur among them. What followed was a beautiful sunny day in Birmingham, 3500 other runners and a whole lot of powdered paint. People ran for other charities, there were children and also people in wheelchairs participated in this event which I'm sure raised a lot of money for good causes. To date we have raised nearly £1240.00, not including the gift aid, and hope that during other events this total can increase.

I have included some photos of myself and my fellow 'runners' and urge EVERYONE to go out and take part in this event, it really is for all ages and abilities – and I can guarantee that the only thing that will hurt by the end of it, is your face from laughing so much!



Rachel Summers

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JUNE LEWIS surprised us at the July drop-in with a lovely cake to celebrate her 70th birthday. June, an Association Visitor (AV) until she moved away, treated us to tea and was able to catch up with old friends and meet new people with MND and their carers.

NATIONAL NEWS

Wheelchair Charter launched – Recently the Wheelchair Leadership Alliance launched a Wheelchair Charter as part of a new campaign *Right Chair Right Time Right Now*.



We are a member of the Alliance and have signed up in support of the Charter. Karen Pearce, Director of Care (South) said: “Wheelchairs can be a lifeline for many people with MND but some people experience long waits to access a suitable wheelchair. This is unacceptable for a rapidly progressing condition like MND. We welcome the publication of the

Wheelchair Charter and hope it will lead to higher quality services for everyone who needs a wheelchair”. [Find out more](#), including how to pledge your support.

RIGHT CHAIR RIGHT TIME RIGHT NOW : Campaign Update

We would like to thank you if you have pledged your support to the Charter and the Campaign, to date, we’ve had 1,916 pledges with an aim to reach 10,000 by the end of September, so every pledge really does count towards raising awareness of the issues facing wheelchair users and will help us get a better deal for Wheelchair users in England in the future.

If you haven’t done so already, we would appreciate it if you could tell all your friends, family and work colleagues about the campaign and encourage them to also pledge their support via the [pledge form](#) on the website.

Did you know there are many other ways you can help support the campaign? The [Right Wheelchair](#) Website has a wealth of resources available for you to use.

- We have the [Wheelchair Leadership Alliance Charter leaflet](#) which gives all the basic information anyone would need about the Alliance, the Charter and Campaign along with an how to pledge your support.
- There’s also a [Personal Appeal Letter from Baroness \(Tanni\) Grey-Thompson](#)

What will really help make a difference and raise awareness would be for everyone to write to their Member of Parliament and their local Clinical Commissioning Group (CCG), if everyone took a few minutes to do this using our [letter template to MPs and CCGs](#) that would help us raise awareness of the issues at a high profile level. The templates are really simple to use, and we’ve included links to enable you to find [your local CCG](#).

Please visit the [Campaign Resources](#) page for more tools to help you spread the word and support the campaign. There’s also a full summary of easy actions that each interest group can take (be you a member of the public, clinician, charity, wheelchair user etc) that can be [here](#).

And finally if you use social media, use those platforms to help inform others about the campaign.

Kind Regards

Nick Goldup

Wheelchair Leadership Alliance Member

Email: alliance@rightwheelchair.org.uk

Website: rightwheelchair.org.uk

Follow us on Twitter: @Rightwheelchair and #MyWheelchair

FUNDRAISING

Douglas Graham, Director of Fundraising, outlines our fundraising promise below:-

You will undoubtedly be aware of the recent media coverage of fundraising practices in the charity sector. We do not use any of the organisations at the centre of these allegations, but I thought it important to reassure everyone who supports the MND Association about the high standards we strive to ensure are integral to all our fundraising activity.

- We make sure we comply with all aspects of charity law by rigorously adhering to the Institute of Fundraising Code of Practice and the legislation on data protection;
- We do not undertake any cold calling;
- We do not share the details of our supporters with any other organisation;
- Should you wish not to receive fundraising communications then all you have to do is tell us and we will make sure you are no longer contacted in this way. All our fundraising communication contains this option to opt out;
- We receive very few complaints, but when we do we take them very seriously, investigate them thoroughly, report them to our Board of Trustees, and take appropriate action;
- We are especially careful when communicating with people with MND who are also supporters;
- Finally, and probably most importantly, the MND Association is part of the MND family and our most important value is putting people with MND, their families and carers at the heart of everything we do. Everyone in the MND family wants a world free from MND and at the Association we want donating, fundraising, and supporting the MND Association in any way to be a positive experience so we will always treat supporters fairly and with respect, and would never intentionally seek to pressurise them in to giving.



Thank you for your continued support. It is only because of you that we can fund research, provide care, campaign and raise awareness. We will never forget that.

If you have any questions please contact our Fundraising Team on 01604 611860 or email fundraising@mndassociation.org

THE OXFORD MND CENTRE

1st UK PLS Day

Friday 23rd October 2015

Oxford Spires Four Pillars Hotel
OX1 4PS

A dedicated day for Primary Lateral Sclerosis patients, carers, and healthcare professionals.

Expert talks on the history, clinical features, pathology, optimal management, and research into PLS, plus patient Q&A session.

Wheelchair-accessible venue

Easy parking

Refreshments and lunch provided

FREE for PLS patients (and one accompanying carer)

All others £75

Sponsored by the MND Association

To register, please email

hjsconference@btinternet.com



One Organisation
Together we make
a difference



AGM and Annual Conference

The MND Association AGM and Annual Conference will take place on **Saturday 12th September** at the Radisson Blu Hotel at East Midlands Airport. The conference is a great opportunity for people with MND, their carers and families to meet each other and to learn more about MND and the care and support available to them. There will also be a range of information and advice stands manned throughout the day by Association staff and external exhibitors.

If you are unable to attend the main speakers and the

AGM will be streamed live and there will be opportunities for you to have your questions asked on the day. You can watch last year's meeting by clicking on the link below.

Watch our AGM On Demand

You can register for this year's AGM and Annual Conference by following this [link and filling out the online form](#).

Email: conference@mndassociation.org

Contact: The Conference Team **Telephone:** 01604 611837

LOCAL NORTHAMTONSHIRE BRANCH NEWS

Northamptonshire Neurological Forum Focus Group – Have Your Say!

The first focus group for people living neurological conditions, organised by the Northants Healthwatch Neurological Forum, took place on August 14th. A small group representing people affected by Motor Neurone Disease (MND), Progressive Supranuclear Palsy (PSP) and stroke met to identify what works well and what could be better in respect of local support services. While some services are good, the group felt greater awareness, education and co-ordination is needed. Another meeting is being planned for later in the year. Tea, coffee and biscuits are provided and the venue is wheelchair friendly. If you are interested in finding out more or would like to attend the next meeting, please contact Rachel Boothman, your Regional Care Development Adviser, for details – rachel.boothman@mndassociation.org

WHAT'S ON

Wednesday September 2nd Drop-in 2pm ---4pm

The Garden Centre Newport Pagnell Road Northampton NN4 6HP

Wednesday October 7th Drop-in 2pm --- 4pm

The Garden Centre Newport Pagnell Road Northampton NN4 6HP

Sunday October 11th Open Meeting 2.3pm --- 4.30pm

MND Christmas Cards Raffle

St Matthews Church Parish Centre 27a The Drive Northampton NN1 4RY

Saturday October 24th 10am --- 12.30pm

Coffee Morning 7 Francis Dickens Close Wollaston NN29 7RH

Cakes MND Christmas Cards, Jams & preserves Raffle .

Advance Notice

Wednesday November 4th Drop-in 12.30pm --- 2.30 pm

The Garden Centre Newport Pagnell Road Northampton NN4 6HP

Wednesday December 2nd Drop-in 12.30 pm --- 2.30pm

The Garden Centre Newport Pagnell Road Northampton NN4 6HP
(to be confirmed)

Sunday December 13th 1.30pm ---- 5pm

Christmas Party Buffet Lunch with Entertainment

St Matthews Church Parish Centre 27a The Drive Northampton NN1 4RY .

Wednesday January 6th Drop-in 12.30pm --- 2.30 pm

The Garden Centre Newport Pagnell Road Northampton NN4 6HP



FOR SALE

Pride GoGo Sport Scooter

As new £550 (List price approx £1700)

Contact chull1@waitrose.com

If you wish to advertise an item for sale in the next (December) edition of the newsletter, please send details by 20th November to chull1@waitrose.com.

We offer a free advertising service, but we cannot accept responsibility for the condition of items advertised. Arrangements for collection of items for sale should be made directly between the buyer and seller. Where specialised or lifting equipment is concerned, you are strongly advised to seek advice from your occupational therapist and the manufacturer as to suitability and health and safety requirements.

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 – 08457 626262 - 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) Rachel Boothman – 08453 751830 rachel.boothman@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.

Drop-In sessions are another opportunity to meet informally. They are usually held on the first Wednesday of every month at the restaurant in the Garden Centre, Newport Pagnell Road, Wootton, Northampton NN4 6HP (next to Waitrose). During the months of April to October we have afternoon tea from 2.00 - 4.00 pm and from November to March we have lunch between 12.30 – 2.00 pm There is no need to book – just come along. 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, Tracey Dixon 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:
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Northampton NN1 2BG

Registered charity number – 294354