

North and East Herts Branch May Newsletter

20
years!

1994 to 2014

The MND association website is: www.mndassociation.org

The National Office helpline is: 08457 626262

Motor Neurone Disease Association – Registered charity No. 294354

Branch Patron: Dr Viv Lucas

Message from the Chair

The attendance at our AGM this year was abysmal and we appreciated the presence of Colin Smith who was the only member, apart from the committee, to turn up! As usual there were no nominations or volunteers for the committee and the present committee was duly returned for another year. It is a cause for concern that we are unable to attract new folk onto the committee as we play a vital role in attracting funds, to be used locally, which would otherwise go to National Office or to other charities. Arrangements are well in hand for the 20th Anniversary celebration on the 30th May and we look forward to seeing those of you, who have responded, on that day.

Here is a brief summary of my report at the AGM.:-

‘Since the last AGM we have introduced a mix of day and evening meetings with more social ‘get-togethers’ which have proved successful in attracting more folk. Donations, proceeds from a range of fund –raising activities and street collections etc. continue to help maintain a healthy bank balance so that we are able to respond quickly to local requests for help as well as contributing to appeals from national office for specific projects and research.

We discussed changing from ‘Branch’ status to a ‘Group’ but decided against this as there would still be a need for a group of people to run this. Our bank account would also be held by the association and could delay our response to requests for help.

Geoff has taken over the organisation of the street collections, as well as his role as treasurer and I must thank him and the members who help on the day. Thanks must also go to Chris, Derek and Alan who produce an excellent newsletter, to our association visitors Chris Jane Lesley and Maria, and to Annette and Jon for producing the revised Branch leaflet and web site. And last but not least thanks to all the committee and Marilyn our secretary for all the work they put in on behalf of the Branch.

In spite of committee problems, the Branch continues to flourish and we appreciate the loyal support of members, which ensures our continued existence and ability to support those with MND in this area.’

Maria is organising a cream tea for the June meeting and there are more details about this in the newsletter. A speaker from the Red Cross has been booked for the July meeting **Wednesday July 30th Bedwell Community Centre** so let’s make sure there are enough folk present to make it worth her while.

I look forward to seeing you at some of these events

Gloria

Fundraising

Let's get baking!

As the craze for home baking continues to sweep the country, the Association are asking budding bakers to don their oven gloves and host a special Bake It event during our awareness month in June. You could organise a vintage cake stall, coffee and chat morning, afternoon tea party, or a good old fashioned bake sale.

Fundraising packs are available from the fundraising team.

To find out more call 01604 611860 or visit www.mndassociation.org/bakeit.

If you are unable to hold an event, but would like to support the work of the Motor Neurone Disease Association please text CAKE00£5 to 70070

Also:

Jim Beaven, husband of the lovely Lesley, one of our Association Visitors, is taking part in the London to Paris Bike ride, he will be raising money for the branch.

Here is his journey information

He leaves on Wednesday the 18th of June and has to cycle 80miles from London to Dover then it is a further 180miles too Paris.

He will ride a total of 260 miles and returns on the 22 June.

The web page for donations <http://UK.virginmoneygiving.com/James Beaven1>

Some further information on the very special Walk to De'Feet with the potential to raise some substantial funding. It takes place on the 29th of June at the Oshwal Centre in Northaw, close to Potters Bar. The 10 KM walk will gather a group of walkers from several different charities including ours. The organisers themselves will be raising money and will proportion this money out based on how much each charity raises. So, the more walkers we have and the more they raise, the more we receive from the Pharmacists. In previous years, the Pharmacists have raised around £40,000, a huge amount! Full details of the walk will be posted to all walkers who register nearer the time, the important points below are:

- Registration starts at 9:00am with the walk starting at 10:00am. It will finish between 3:00 and 4:00pm
- The start and finish point will be the Oshwal Centre, Coopers Lane Road, Northaw, Herts, EN6 EDG
- The route will be marshalled, with refreshments and free hot lunch at the end
- A shorter route for those in wheelchairs is available.
- There is **NO** min sponsorship although there is a suggested sponsorship of £50
- Open to all ages
- Trophies for all under 16's and the highest three adult sponsor forms

Could you please contact Michael Thelwall as soon as possible as we need to know how many people could be potentially interested,

michael.thelwall@mndassociation.org and he will register your interest.

This is a fantastic opportunity to raise some serious money and to raise awareness of our cause.

Catherine Henderson has arranged a fund raising concert with the group that she sings with, From the Top, on Sunday 29th June at 3pm in St Andrews's Church Hertford, in memory of her mum Cathy. Entry will be free, but there will be a collection afterwards.

Tea and cake will be served, but Cathy would be very grateful for help with refreshments. From the Top are an 8-voice unaccompanied vocal group and sing a wide variety of music.

The programme for this concert is based on the theme of birdsong. Cathy would like to serve tea and cake in the interval as her mum was a great cake maker. Contact Cathy on 01992 511448 , or email, cat_hen@hotmail.co.uk

Past events

The street collection on 26 April went well. We were fortunate that the rain held off, and the people of Royston proved generous. A total of £328.71 was raised, up from the previous year. Many thanks to the intrepid collectors who gave their time and energy to reach that figure.

Our next collection date is approaching fast, that will be in Letchworth on Saturday, 7 June. I would be delighted to hear from volunteers to help with that one.

For future reference, the last date of the summer will be in Hitchin on Saturday, 26 July.

Geoff

Our Speaker at the AGM

We were very privileged to have the pleasure of listening to Karen Pearce, Director of Care for the MNDA at our AGM on the 30th April, which was missed by so many.

Karen described what was a very successful year for the Association telling us the financial position was much more stable, there was more support provided through volunteers, MND Connect, regional teams and financial support services with an excellent year of awareness raising. There had been another brilliant International Research Symposium and the NICE guideline on MND is starting.

She said improvement was still needed in shortening time to diagnosis, increasing in the number of people with MND referred to the Association, also improvements to social care and better integration of health & social care. There were more people accessing specialist MND multidisciplinary care and improving support to carers and children.

There is an important new aspect of our strategy in response to strong feedback through the consultation process, we have added Campaigning and Awareness Raising alongside Care and Research. The vision remains the same accept A World Free From MND.

The Association has three mission areas:

- To improve care and support for people with MND, their families and carers.
- To fund and promote research that leads to new understanding and treatments and bring us closer to a cure for MND.
- To campaign and raise awareness.

There have been recent achievements in care with 19 Care Centres, 8,000 MND Connect enquiries per year, approximately 320 AV's supporting 1,300 people. There have been wheelchair and volunteer grants, 1,000 pieces of equipment have been provided with financial support of £400,000 (422 people) plus a Red Flag project with GP's.

Karen told us she had National Responsibilities which included 9 Care Centres/Networks. Support services included Equipment Loan and MND support grants plus Care Administration lead by the Projects Team. Karen also gives support across the Association as a Data Protection Officer, responsible for Campaigning - influencing specialist services, Fundraising and Research of health and care related work. She told us that Staff and Volunteers continue to increase our understanding of the needs of people with MND and their families. She said Volunteers and staff are working in partnership and there is a strong partnership with our branches and groups.

Also there had been improved recruitment, training and support which better reflects the needs of people living with MND from diverse backgrounds. Finally she told us 'We are all part of the Association Jigsaw'.

Our grateful thanks go to Karen for such an enlightening talk given us in such an interesting way.

Marilyn

Coordinator post made permanent in Hertfordshire

Local NHS decision makers have agreed to fund an innovative post that supports people living with motor neurone disease (MND) and other rapidly progressing neurological conditions in Hertfordshire, following calls from local people and the MND Association.

Herts Valleys and East & North Hertfordshire Clinical Commissioning Groups (CCGs), who buy NHS services for Hertfordshire, have confirmed that they will fully fund the post of Specialist Neurological Conditions Coordinator after charitable money from the MND Association and The John Ellerman Foundation ends.

The role has had a big impact since its introduction in 2011. As well as achieving cost savings by reducing the number of unnecessary admissions to hospital, it has improved the quality of life and experience of people with these devastating diseases.

The post was formerly held by Liz Garrod, the new postholder will be starting in the next few weeks, exact date to be confirmed.

Thinking of a holiday

The holiday season is upon us again, a few ideas to set you thinking.

MAISON DES LANDES HOTEL, JERSEY.

It is situated 9 miles from St Helier with panoramic views of St Ouen's Bay and the Atlantic. The hotel has specially adapted minibuses to take guests, at no extra charge on daily sight-seeing outings, some evening excursions. Highly recommended
Website:- www.lionsclubofjersey.co.uk. - Telephone 01534 481683

THE GROSVENOR HOTEL, WESTCLIFF ON SEA

Overlooking the seafront, minutes away from Southends beaches, Cliff Gardens, Pavilion theatre. Entertainment on most evenings. Trips out to local attractions in the hotels wheelchair friendly mini bus
Telephone 1702 345365 - www.grosvenorwestcliffe.co.uk

THE WEST SHORE, LLANDUDNO

Situated where the twin limestone peaks of Great and Little Orme meet in Llandudno. The hotel is owned by a charity Livability, formerly John Grooms, designed specifically for people with disabilities. Within easy reach of the Snowdonia National Park, Isle of Anglesey, Conway Castle.
Telephone 01492 8768

OPEN BRITAIN – is a guide book and website for information on UK tourism and Holidays for people with disabilities and specific access requirements.
Telephone 0845 124 9971 – www.openbritain.net.

Other useful information:

ACCESS TRAVEL – holidays and insurance for disabled people.

FREE SPIRIT TRAVEL INSURANCE -0845 2305000 –
freespirittravelinsurance.com

FREEDOM TRAVEL INSURANCE – 01223 446914 –
freedomtravelinsurance.co.uk/

TRAVEL INSURANCE MEDICAL – 0844 6928449 – travelinsurancemedical.co.uk

J.D TRAVEL INSURANCE CONS – 0844 2474749 – jdtravelinsurance.co.uk

PULSE INSURANCE – 01280 841430 – pulseinsurance.co.uk/

The Association has an information sheet No 3 with useful advice.

FUTURE MEETINGS AND EVENTS FOR YOUR DIARY

May
Friday 30th
6pm – 8pm

Celebrating our 20th Anniversary of the Branch
The Civic Centre, Prospect Place, Welwyn, AL6 9ER

June
Saturday 7th

Collection in Letchworth

June
Wednesday 25th
3pm

Cream Tea at Pearces Garden Centre
Please contact Maria if you would like to attend.
Tel numbers 01920 422980 and 07800 978281 (mob)
Email: maria.watson11@ntlworld.com

Traditional English Afternoon Tea

Warm Homemade Scone with Jam & Clotted Cream,

Finger Sandwiches

free range egg & cress, organic smoked salmon & cucumber, honey glazed ham with mustard.

Pearce's Home Baked Cakes or Pastries, with a choice of Tea or Coffee£8.95

July
Saturday 26th

Collection in Hitchin

July
Wednesday 30th

Meeting at Bedwell
Denise Norman
Volunteer British Red Cross Care in the home service

August

No meeting

Bedwell Community Centre
Bedwell Crescent
Stevenage
SG1 1NA

Bedwell meetings are the last Wednesday of the month at 7.30pm

BRANCH MANAGEMENT COMMITTEE – 2012/13

OFFICERS

CHAIRMAN	TREASURER	SECRETARY
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BRANCH CONTACT

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THE MND NORTH HERTS WEBSITE

www.mnd.n-herts.freeuk.com

THE MND HELPLINE

Tel: 08457 626262

All calls are charged at local rates. The hours of opening are:-
Monday - Friday 9.00 a.m. - 5.30 p.m. and 7.00 p.m. - 10.30 p.m.
Saturday, Sunday & Bank Holidays: 10.00 a.m. - 6.00 p.m.