



CAN YOU HELP?

YAMND

MANAGEMENT COMMITTEE

Chair:	<i>Kate Adams</i>
Secretary:	<i>Claire Halstead</i>
Treasurer:	<i>Audrey Halstead</i>
Membership Secretary:	<i>Adryenne Hope</i>
Members:	<i>Sheila Sykes</i> <i>Lesley Holroyd</i> <i>Liz Allen</i> <i>Janet Sharpe</i>

York & District
Against Motor Neurone
Disease

REGISTERED CHARITY

No. 1000356

TO AVOID CONFUSION

York Against Motor Neurone Disease is a local charity quite separate from the National organisation Motor Neurone Disease Association. It is managed by a team of local volunteers for the benefit of local patients.

Without the support of the innumerable people who play a part in the running and funding of YAMND, none of the people with MND in the York and District area would benefit from the resources provided by the Charity. Primarily, people with MND and their families find the service of our nurse, Doreen Foster, invaluable. The Charity also seeks to provide equipment to improve the quality of patients life where possible, as emphasised by the experiences of Kevin Lewis and his family on page 2. Without the effort of all who contribute we will not be in a position

to continue to provide these services indefinitely.

In the past, people in and around the York area have undertaken a wide range of fund raising activities including golf days, marathons and walks, calendars, balls, street collections and quizzes. These events have been enjoyed by all involved, and have raised huge amounts of money to enable the Charity to keep going.

In addition to fund raising, there are also opportunities to assist by joining the committee. The committee meets bi-monthly at York Hospital to discuss issues and fund raising ideas and has benefitted from several members in the past who have worked tirelessly to ensure that a consistently high level of care and support can be provided to patients in the local area. In particular, thanks must go to Leslie King, Pauline Coldrick and Janice Oxtoby who have all recently stepped down from the committee after many years service.

A big thank you must go to all those involved in supporting YAMND in any capacity through the years, but we are eager to recruit new members to the committee and need everyone to continue in their fund raising efforts.



Chris Howard, Sue Moore, Stuart Newton and James Allingham present Sheila Sykes of YAMND a cheque for £4,715 on 9th May 2008 at Pike Hills Golf Club following the Yorkshire Water Golf Day

MISC. DONATIONS

Arlish & Chambers	£150.00
C Dolling - 50th Birthday	£120.00
D Mowse	£101.32
A Holliday	£100.00
B Punt (Clifton Meth.church)	£230.00
Easingwold Bowling Club	£125.00
H E Beadnell- Seals - wedding	£1,375.00
C R Hutchinson	£110.00
M Blacker	£440.00
Birkenshaw pensioner Ass	£200.00
L Stevenson	£310.00
J Mellor	£100.00
G Finn	£100.00
S Robinson/Miss Bradley	£100.00
N Duffield School.	£234.00
Masham Ladies Golf club	£100.00
Mrs B Loveday	£826.00
Mr & Mrs Pinder - 50th wedding ann.	£150.00
Yorks Countrywomen Ass.	£600.00
St. Edward the Confessor	£1,712.59
J Goodburn	£150.00
	£7,333.91

MEMORIAL DONATIONS

R Frith	£622.00
P Blacker	£1,910.00
D Banks	£325.00
E Stipetic	£250.00
R Calvert	£206.00
S Watson	£100.00
S Tyler	£595.00
O Bairstow	£100.00

B Midgeley	£136.00
B Finn	£130.00
M Robinson	£100.00
F Duxbury	£162.00
P Andrews	£216.00
M Thompson	£260.00
	£5,112.00

FUND RAISING

Bubwith Quiz	£600.00
Clara Tumber - London Marathon	£1,275.00
G Hamilton - Dublin marathon	£1,000.00
Haxby Meth Church - charity walk	£650.00
M Wainwright	£140.00
NEC charity ball	£3,000.00
Quiz Night - Stillington	£210.00
Rotork plc - golf Day	£100.00
Yorks Water golf Day	£4,715.00
York Street collection in May 2008	£411.10
	£12,101.10

YAMND - Fund raising, Misc donations and memorial donations over £100

www.justgiving.com

If you would like to make a donation to YAMND via the Just Giving website, which enables us to automatically claim Gift Aid on your donation, please go to www.justgiving.com/yamnd and click on the "Donate" button. Similarly, if you are interested in collecting sponsorship for YAMND, you can set up a sponsorship site by clicking the "Raise Money" button.

Family thanks YAMND and Fundraisers

My husband Kevin Lewis (aged 46) was diagnosed with Motor Neuron Disease in June 2007. It was, and still is a massive shock to our family which we have been supported to come to terms with by Doreen Foster and the team at York District Hospital.

Kevin did really well for the first 15 months – continuing to work full time and to lead a relatively normal life. But then suddenly in September 2008 his breathing began to be affected by the disease and he started to experience respiratory failure. I remember being told that my husband “wasn’t long for this life” and that he possibly only had weeks or even days to live. It was the most devastating and heartbreaking news. However we were told that Kevin’s breathing could be supported by a NIPPY 3 machine which could buy us quality if not quantity of time. Even this small blessing was something we wanted to try for. From the first night that Kevin used the machine the transformation was amazing. His oxygen levels normalised and he was adamant that he was leaving hospital the next day. And that’s exactly what happened. He came home with the NIPPY 3 machine and is still here five months on. He uses the machine through the night and sometimes during the day if he is feeling especially tired. He has recently had a feeding tube fitted and the NIPPY 3 machine was used to help him get through this procedure.

The machine which has saved Kevin’s life and given him and our family this precious time was bought through the kindness of peoples donations to YAMND. We can never thank those people enough – they have ensured that Kevin was able to access a piece of equipment which has saved and sustains his life. That kindness has given our little boy – Adam – time with his Daddy and Kevin the chance to continue fighting motor neurone disease. Thank you.

Kevin, Anne and Adam Lewis.

Nurse's News



Another year has passed so quickly and here I am in March 2009 again trying to recall all that has happened

since my last news report. For the people and families we care for it will have been a year that they will remember for the many difficulties they have had to contend with and the altered future that lies ahead of them, hopes of what might have been, replaced by the battle they face fighting the effects of Motor Neurone Disease.

Last year I reported on the sudden closure of ward 38, where those with neurological conditions were cared for. Unfortunately, much as we expected, the closure has had a detrimental effect in that the continuity of care which is so important has been lost. Many of the wards which were closed during the cuts of 2007 have been reopened, including ward 38 but this is no longer a neurology ward. We can only hope that at some time in the future the much needed specialised staff and facilities will be provide again. After all 25% of people admitted to hospitals suffer from a neurological condition, specialised care is of the utmost importance.

This year occupational therapists, and physiotherapists have accompanied me for a day to see what my job entails. Since the closure of ward 38 I have not had any student nurses out with me which is a pity as in past years they all said they learned a great deal about the disease by spending a day with me seeing patients in their own homes. I have also spoken to groups of district nurses, and did a teaching session for nurses and carers at St Leonards Hospice.

St Leonards Hospice has been undergoing Government funded alterations which has meant that some of the beds were out of use during the building works. For a few months only 16 of the 20 beds were

in use and at the beginning of this year there were a few weeks when only 6 beds were in use. Things are now getting back to normal, beds are reopened and building work is well advanced and the rooms have been decorated and new TVs etc fitted by each bed.

Again the hospice provides excellent care and support when needed for our MND patients and their families, as well as the fantastic support they give me. Some attend day care which gives them a chance of a day out, meeting other people and trying different things, (some wonderful previously unknown artistic talents have been found and nurtured), enabling family to have a few hours to do things they otherwise would not be able to. Respite care is also offered to people with MND, they receive excellent care and pampering! In very comfortable surroundings, whilst also receiving expert medical and nursing care. I thank all the staff there for everything they do.

There have been several television programmes about MND this last year and some of the coverage has caused a lot of concern to people living with MND. One thing which was not made clear in some of the reports is that 90-95% of cases are sporadic, with no family history. Therefore only a very small percentage of cases have the inherited form. In the 13 years I have been working with people with MND I have never met anyone who had a family history of MND.

This year our new management team is now up and running, Kate Adams our Chairperson and Claire Halstead our secretary joined the team and quickly seem to have got to grips with things. Ann Stewart who joined the committee has had to resign recently due to illness but we wish her a speedy recovery and thank Ann for her help over the past months.

I attended the first day of the International Symposium on MND with Kate Adams last November which this time was held in Birmingham. We met and had chance to speak to some very interesting delegates from all over the world. We also had chance to chat with Dr David Oliver a palliative care

consultant with special interest in MND. I often lend to patients and families a book written by him 'Motor Neurone Disease a Family Affair' comprehensive and easy to understand.

I also attended a very interesting study day in Halifax for advanced practitioners. This was organised by The Motor Neurone Disease Association. I also has the opportunity to speak to other doctors and nurses from around the north of England and we exchanged information on what services were available in our respective areas.

I am always impressed by the courage and fortitude of the people and their families we care for. Kevin and Anne Lewis have very kindly written an article for the magazine regarding the NIPPY 3 machine which he is currently using. This is a non invasive ventilator which helps to support weakened respiratory muscles and helps improve quality of life by increasing energy levels and helping to improve appetite. The machine is compact and can be used easily at home, usually overnight, resulting in a more restful nights sleep. The money for this was raised by family and friends of someone we cared for and was donated by us to York Hospital for the use of anyone with MND and I know they will be pleased to hear that it is continuing to make such a difference for another family. Thank you Anne Kevin and Adam for making time to contribute to the magazine.

Other people continue to raise money to enable us to continue caring. Yorkshire Water staff organised a golf day at Pike Hills Golf Club. Teams of players including Shelia Sykes, one of our committee members had an enjoyable day of golf. I was invited to the delicious dinner which followed, after which I spoke about the work of the charity (I suppose you could say singing for my supper!). I then helped to draw the raffle, there were some fantastic prizes all of which had been donated. It was a very successful day which raised over £4,000 and thanks to everyone involved both from Yorkshire Water and Pike Hills Golf Club.

Another family undertook the three

Yorkshire peaks climb on one of the hottest days of the summer, they all succeeded in completing the climb and raised vital funds

Kate will speak in her article about the fundraising Ball which was held, so I will leave those details for her to report on.

Deborah McStay is running a half marathon for us on 12th July. The link to her fundraising page is www.justgiving.com/mcstaydeb. Deborah is a friend of Kevin Anne and Adam Lewis and she says "Money raised will enable the York Against MND charity to continue to provide practical help to Kevin and his wonderful family and also families like them."

Clara Tumber is again running a marathon for us. She previously ran the London Marathon in memory of her mother this time she is having a change of scenery and running the Edinburgh marathon in May. Anyone who wants to sponsor her can do so by visiting www.justgiving.com/claratumber. Others are also busy training for 10k runs and doing other fundraising activities, we thank them all for their efforts as it is only with such help that we survive as a charity. This is especially true during the present economic difficulties, so we are extremely grateful to everyone who works so generously to support YAMND.

This year we are expecting to see the start of the Lithium drug trial. Sheffield is one of the centres where this will take place. Hopefully there will be other trials on offer later in the year.

Finally my thanks to all the neurology team at York Hospital who always respond quickly to any requests I make on behalf of patients and to the support they give me. Also the YAMND management team who have always given me their unfailing support.

Doreen Foster



Chairperson's Report – Kate Adams

I am delighted to be able to contribute to this, my first YAMND annual newsletter as Chairperson. I do enjoy my involvement with YAMND and the vital work it is doing and look forward to the coming year.

July 2009 is the twentieth anniversary of the Association and everybody has achieved so much in our area for all those affected by MND. In this newsletter I would like to explore ideas of how we may ensure the continued successful work of YAMND for a further twenty years and meet the changing needs of those we care for.

Claire Halstead, our new Secretary, whose role is crucial to the successful running of the Association, has a considerable workload and she has already proved to be a fantastic asset, she is extremely dedicated and her ongoing hard work has continued to impress us all.

Doreen has again fulfilled a pivotal role within the Association. As ever she has faced the many challenges head on, the closure of Ward 38 at York Hospital and the temporary reduction of beds at the Hospice have impacted greatly upon Doreen's role and workload. Doreen managed this with her usual calm proficiency, care and compassion reducing the potential impact upon the people she cares for. Thank you Doreen; your contribution is invaluable.

I was sorry to receive Ann Stuart's resignation from the committee and I would take this opportunity to thank her for her unstinting involvement in the committee and wish

her a speedy recovery.

People's efforts to fundraise are humbling and I wish Deborah, Clara and Jayne the very best of luck running their marathons and would like to thank all fundraisers for their financial contribution and raising the profile of YAMND. We were fortunate to receive a donation from the North Eastern Circuit of the Bar in memory of Robert Terry. They held a Charity Ball in June 2008 at The Railway Museum York. Fundraising is essential to our ongoing survival and without everyone's efforts we would not be the success we are today.

I endorse Doreen's views, as expressed in her update in this newsletter, concerning the lack of student nurses gaining exposure and experience of how to care for people with MND. I feel passionately about investing in the nursing profession and workforce through supporting our nurses learning, to enable them to be able to deliver the best possible care for this client group. As part of this I will be looking towards establishing links within the University of York.

Our focus for 2009

- The major focus will be the need to ensure our *financial position* is secure to allow us to continue to fund our MND nurse. Fundraising and donations are key to this.
- The change in *provision of specialist neurological services* at York Hospital is of great concern. I have contacted the Chief Executive of the Trust to discuss our views but as yet have not had a meeting confirmed. It is essential that YAMND has a voice and open channels of communication with our local Trust

and I intend to pursue this in my role as Chair. I am hopeful that there will be positive changes to the provision of neurological services at the Trust and will keep you up to date with any news I may have.

- Ensuring that *we meet the needs* of those with MND, their families and carers to the best of our ability. I am looking forward to working with Doreen and the committee to consider how we can best do this in the current climate. There are a number of people who have offered support and it is hoped that we may be able to have educational events, support meetings and more community based work during the coming year.
- Sharing ideas with *other similar organisations* will be helpful in keeping us up to date and I hope to explore ways in which we can do this.
- The role of the media is vital to our future. We need to be visible in so many areas and this is one area where we do need some specialist help and support. We are keen to *increase the membership of our committee* and would like to hear from people who have not only specialist skills but enthusiasm for our Association to contact me or any committee member.

Lastly I would like to thank all of those of you involved with YAMND for your continuing support and commitment; this means so much.

Kate Adams - Chair

Our terms of reference

MND is a devastating illness which affects some or all muscles and can also lead to loss of speech. There is no cure but much can be done to help those affected, particularly by the provision of mechanical equipment.

York and District Against Motor Neurone Disease operates within twenty miles of York District Hospital. A part-time MND Nurse is the only paid appointment and there are no premises to maintain. Therefore, expenses are minimal and a very high percentage of all money raised is used to help sufferers and their families in the York area. Money is also used to further research into the cause of MND.

MND can strike anyone, anywhere, at any time. It afflicts people from all walks of life and of both sexes. Apart from it normally being diagnosed from the age of 40, there is no common denominator and it is completely random in its choice of sufferers.

Our Patrons

THE Patrons of YAMND are
Dr P. Crawford, MB, ChB, MD, MRCP;
Dr A. Heald, MB, BS, MRCP, MD.
and
Prof. P. J. Shaw, MB, BS, FRCP, MD.



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