



News from York & District Against Motor Neurone Disease No. 18 October 2010



Welcome to our annual newsletter for 2010. YAMND had its 21st birthday this year! YAMND continues to provide practical and emotional support for people affected by Motor Neurone Disease (MND) in the York area.

Last year Doreen Foster, our MND nurse, wrote a poignant introduction to her Nurse's news, part of this was about "the altered future that lies ahead". Many of you will know already that Doreen has undergone treatment for cancer this year. She is such a fundamental part of YAMND and her absence has been felt by so many who have a heartfelt concern for her wellbeing. We all send our very best wishes for her recovery. The people that she has been unable to visit have missed her. Doreen's absence has presented a challenge for the charity in terms of continuing to provide patient care. St. Leonard's Hospice has stepped into the breach and offered us invaluable support. YAMND pays St. Leonard's Hospice for Jill Freeman, who is a registered nurse and part of

the Hospice At Home Team, for one day a week. She currently has a caseload of nine patients.

Within my role as Neurology Nurse Specialist at York Hospitals NHS Trust I have the rest of the patient caseload. Whilst we have made every effort to maintain a quality service, it must be acknowledged that the level of service has changed. However, all patients are seen when they need us. St. Leonard's Hospice offers a 24-hour helpline that people with MND can access and my patients know they can call me at any time. The Neurosciences Multi-Disciplinary Team, Sue Spence and all the team at St. Leonard's Hospice have been a fantastic support and I personally would like to thank them for this.

As part of my role, I did a teaching session for York LINK covering a wide variety of topics on the care of people with MND, and hope to be able to offer further training and support to individuals or groups as requested.

The bed base for Neurology patients is still under review at York Hospital. Doreen and I had meetings with the Chief Executive, Patrick Crowley and Chief Nurse, Libby MacManus to highlight the needs of people with MND who are admitted to the hospital and we will continue to work with them as they seek to improve the service for people with MND and other neurological conditions. Juliet King, Sister of Ward 32's where the majority of neurological patients are looked after at the moment, is very supportive of any initiatives that will support and improve the management of people with MND.

We hope you will find this newsletter interesting and are delighted to have contributions from Mrs Miller, who has written about her husband Peter Miller who has most generously donated his amazing stamp collection to YAMND; our new chair Hazel Allison who has written an article about her mum, and we have also had contributions from Professor Shaw, Jill Freeman and Keith Bell. I took on the role of Chair whilst I was on maternity leave with my first daughter and have continued, after a brief return to work and further maternity leave break following the birth of my second daughter. Now that I have returned to work within Neurosciences at York Hospital, I decided it was appropriate to stand down as Chair to ensure that there is no conflict of interest. I am absolutely delighted to inform you of Hazel's appointment as Chair and know that she will play an active, positive role and make a significant contribution to the running of the charity. I wholeheartedly welcome her. I very much look forward to contributing to fundraising activities and will continue to be on the committee of YAMND, and play an active role in linking in with the hospital.

It is an absolute privilege to care for those affected by MND and the people important to them. I would like to take this opportunity especially to remember those who have died within the last year. Our sympathy and condolences go out to all their loved ones.

Finally I would like to thank all of you who have given me and the Charity such fantastic support in the past year. To those of you who have bought raffle tickets, to be drawn on 18th December 2010, I wish you the best of luck in winning one of the generously donated prizes.

YORK AGAINST MOTOR NEURONE DISEASE

Reg Charity No: 1000356 www.yamnd.co.uk

Peter Woodhouse Miller, by Mrs Jean Miller

Peter was born and grew up in West Hartlepool, Co Durham. He served his National Service in the RAF and when he was demobbed from there he joined the National Power Generating Board as a Shift Control Engineer working at the Billingham Power Station. We married in 1957 and Jonathan was born in 1960.

When the Power Station closed he transferred to Stella Power Station on the Tyne and we lived for ten years in Washington. Among Peter's hobbies were sailing from the Tees Sailing Club, he was an Advanced Motorist, a member of the Washington Camera Club, a keen Ten Pin bowler and a Green bowler and when he retired we came to live in Wombledon and he greatly enjoyed planning and looking after our extensive garden. His more sedentary recreation was his stamp collection which I think he began in about 1952. He always said he would discontinue it at the end of Queen Elizabeth's reign but his illness prevented him from doing that.

From the moment he was diagnosed with MND in December 2007 we received amazing support. The first person we met, apart from Dr Heald (the consultant), was Doreen Foster. We came to know her very well from all her regular visits and we knew that if we had any kind of problem as the disease progressed, Doreen would have the answer. She was most sympathetic and caring, and could direct us to the Physio and Occupational Therapists and could arrange for aids as necessary.

Because we both appreciated very much the help which was available to us, Peter asked me if I would agree to him giving his extensive stamp collection to York and District Against Motor Neurone Disease, and this is being arranged. Peter died on Good Friday, 2nd April, this year, and I can honestly say that his end was quiet and peaceful and I am so grateful that he didn't have to travel the full journey.

It hit like a bolt out of the blue, Mum had Motor Neurone Disease..., by Hazel Allison

Mum and I had always been very close, we spoke every day on the phone and spent much of our time together. Mum was in her 80s but even after having suffered a small stroke was still living independently and was always busy in her garden or looking after family or neighbours.

Easter 2009 came and Mum began to slow down quite significantly and struggled to use her voice and swallow tablets. Her GP and stroke consultant suggested this was caused by constant 'mini strokes'. Mum accepted this but her condition deteriorated almost daily and within weeks she had lost use of her voice and her muscle strength was poor. Mum was admitted to hospital in June after having fallen on numerous occasions. The family assumed that Mum would be treated for the 'mini strokes' and perhaps might once again be able to live in her own home.

In the hospital we received very little information about what the problem was thought to be even though it was obvious the situation was worsening. The total aim seemed to be to get Mum discharged back home although by now she could not stand or barely swallow without choking.

It was Professor Shaw who delivered the devastating news that Mum had Motor Neurone Disease, it left us numb and Mum confused and frightened. The staff on the ward seemed to have little understanding of the disease and it was suggested that a nursing home would offer the basic nursing requirements. Mum was transferred to a nursing home where again staff were unable to offer the specialist care required. It was then that Doreen Foster (on behalf of York Against Motor Neurone Disease) entered our lives and assisted in every way from then on.

Mum had been diagnosed with the most aggressive form of MND and so Doreen took over the situation and arranged for Mum to be admitted to St Leonards Hospice. Mum only spent a few days in the Hospice where she was treated with respect, care and compassion.

We lost our lovely Mum in September 2009 but will always be eternally grateful to York Against Motor Neurone Disease for their fabulous support in the form of Doreen who made a difficult situation bearable. Long may YAMND continue to support people of York and surrounding area in the quiet efficient way they do.

A Message from York Teaching Hospitals NHS Trust Patient Experience Team

York Hospital NHS Foundation Trust values comments from all our patients. We encourage patients to contact us when they are unhappy with our service to help us identify any areas that we need to improve and to tell us when things go well.

You can contact us by letter, fax, email, telephone or by calling in at to the Patient Advice Liaison Services Desk (PALS) in the hospital, where a friendly colleague will assist you with any concerns that you might have.

You can write your comments on our feedback leaflets, which you will find throughout the hospital. You can either place them in the secure box on the PALS desk or you can put them in the post. A stamp is not required.

Alternatively, you can raise your concerns by making a complaint. We will carry out a full investigation into your concerns and provide a written response. If any action is required, we will draw up a plan and ensure it is carried out.

We will not discriminate against you if you make a complaint. We want to improve our services for everyone and value your comments and feedback. Thank you.

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SITraN:

An exciting new MND Research Institute in Sheffield

Professor Pam Shaw and the MND clinical care and research teams at the Royal Hallamshire Hospital/University of Sheffield have worked during the last 4 years to create the Sheffield Institute for Translational Neuroscience (SITraN). The vision behind this development is to bring together under one roof scientists and clinicians of the highest quality from around the world to focus on advancing our understanding of the causes of motor neurone disease (MND) and developing new approaches to treatment which will prevent motor neurone injury. The Institute will allow researchers to harness existing new developments in neuroscience and translate these into benefits and improved outcomes for patients with MND. The new building consists of 2800m² of research laboratories, offices and meeting rooms and is located within the central University campus on Dorset Street just across the road from the Royal Hallamshire Hospital. Building work started in the summer of 2009 and will be completed by mid-August 2010. The team is now beginning the exciting phase of ordering the equipment for the state of the art laboratories and of attracting high calibre researchers to come and work with the Sheffield MND research team.



The SITraN development has required funding of £17m which has been raised with tremendous support from the University of Sheffield, the Patrons of the Sheffield Institute Foundation, the Wolfson Foundation and government funding and many people of generous spirit locally, nationally and internationally. The Duke of Devonshire has given his support as an Honorary Patron and heart warming local support has come from DLA Piper, Abbeydale Golf and Tennis Clubs and the boys of Birkdale Preparatory School.

For Professor Pam Shaw this is the realisation of the dream of her working life. She states:

“The creation of SITraN will enable us to double our research capacity and will I believe underpin a step- change in our ability to improve the outlook for people and families facing MND”.

“The continuation of the long-standing support of York and District against MND for the research programmes of the Sheffield team will be of crucial importance for our future work. This support has helped us a great deal over the last few years and we are really appreciative”.

Please do look out for the announcement of the official opening of SITraN later in the year – where the teams which make up the Sheffield Care and Research Centre for Motor Neurone Disorders plan to thank and celebrate all those who have given their support to allow the vision of SITraN to become a reality.

A new role for Jill Freeman

I have worked as a nurse at St. Leonards Hospice for over eight years and in this time myself and the unit got to know the wonderful, Doreen Foster whilst caring for some of her patients. Earlier this year Doreen took me round her "patch " so that I could gain some insight into how people with MND managed in their own homes.



This turned out to be an invaluable two days as I was asked in April to support some of Doreen's patients whilst she is away, for one day a week and what a time I have had!

I quickly realised what an amazing support and friend she was to her clients. The feeling was, if you needed anything Doreen would have it sorted by the next day at the latest! "Blue Badge?

No problem!" How could I replace this five star service one day a week ? Thankfully for me it is

apparent that only nice people acquire MND and I have been warmly welcomed by everyone.

My eyes have also been opened. The lives of not just the person with MND but their carer, usually a spouse or close family member have increasing demands made on them both physically and mentally as the disease progresses and this is met with great acceptance and stoicism. The Hospice has also been extremely tolerant towards my requests for respite beds although it was felt at times that I was trying to fill the place!

Trying to gain funding towards care to allow people to remain at home with help is such a slow, complicated process that by the time it is either granted or denied it is quite often too late which is terribly frustrating for all involved. This has to change but how?

Overall, frustrations aside I am thoroughly enjoying this role mainly due to the lovely people I meet and I would like to thank them for putting up with this less than five star service for the last six months!

Donation of funds from Minster Lodge

In August this year Master Peter Hart and Charity Steward Keith Bell of Minster Lodge presented Kate Adams (YAMND Chairperson) with a cheque for purchasing a special chair for use by people with MND.

Keith Bell explains more: "Freemasons are taught to practise charity and to care, not only for their own, but also for the community as a whole, both by charitable giving, and by voluntary efforts and works as individuals. Minster lodge is proud of its charitable work and has helped many local York charities/organisations over the years. I was personally interested in supporting a local charity in the York area that did work in helping the sufferers of Motor Neurone Disease; this was due to having a friend who had recently been diagnosed as having this devastating illness. After talking to Kate Adams it soon became apparent that YAMND was most suitable for our lodge to support. Kate and the O.Ts at the hospital explained the need to have a specially designed chair which would make life much more comfortable for a person with MND. After having a demonstration of the electrically operated Duo Major chair at York hospital I was happy to go back to my lodge and ask the members to provide funding for this chair, and an amount of £300.00 was donated. I also submitted a successful grant application to the Provincial Grand Charity for Yorkshire North & East Ridings asking for their support. I was delighted to inform Kate that we had raised a total of £2,888 to purchase the chair.



Bev Richmond, OT; Peter Hart, Kate Adams, Keith Bell

YAMND were delighted to receive their new acquisition of an electrically operated chair designed to make those people, who are affected by this most debilitating disease, as comfortable as possible. The latest electrically operated gel seat model enables them and their carers to adjust the position of the chair which helps to reduce sores, making life much more bearable. It has to be said however that Freemasonry is not all about charity but it does form an important aspect of our lives, it can be said to be the cornerstone of our society. We are a society who enjoy ourselves and have fun with our families and friends."



Upcoming Fundraising Events

We have had some successful fundraising events this year. YAMND ran the cafe and stalls at St. Crux on 3rd February this year

and, despite it being early in the year and our first time, the weather was cold but bright and the day was a huge success, raising almost £1,000! A big thank you to everyone who helped out. This year's city centre street collection was also a surprise success. Recent years had shown a downturn in the amounts collected but the collection was amended from 9am-1pm to 10am -2pm and we collected almost £500. Again, thank you to all who were involved.

We hosted a coffee morning at Heworth Methodist Church Hall between 10am and 12 noon on Saturday 18th September. The Hall; where YAMND's first coffee morning was held 21 years ago; regularly allows charities and other organisations to hold coffee mornings there. Ken manned the book stall; Hazel sold fabulous homemade cakes and produce whilst Audrey, Claire and Kate kept the kettle boiling! £252.66p was raised – brilliant! There are several fundraising events already in the planning stages for the next twelve months. We are hoping to arrange bag packing at local supermarkets, a bucket collection at the Theatre, and a presence at the York Annual Charity Market next year.

Date for Your Diary so far:
Raffle drawn 18th December 2010
St. Crux 18th March 2011
Street Collection 28th May 2011

If you are interested in helping out in any way with our fundraising efforts please contact YAMND Secretary, Claire Halstead, on 07939 030701 or chalstead@hotmail.co.uk

Thank You!

As well as fundraising, a large part of running a charity involves understanding various legal issues, including employment law and probate (when people are kind enough to remember us in their will) which can be very complex. Hethertons Solicitors, in particular Jo Yeates and Simon Crack, have been extremely helpful in providing advice and support in this regard and we would like to say a huge thank you to them for assisting in what can be an onerous obligation for the Trustees.

A huge thank you to Mark Smith of York Graphic Designers for updating our website and making it extremely user friendly. See the fantastic results at www.yamnd.co.uk.



A thank you from Kate to the Pig and Pastry on Bishopthorpe Road, for donating supplies for her St. Crux baking efforts! Thanks must also go to Dean at GT Graphics for his patience with the printing of the newsletter and importantly to Lumley Associates for sponsorship of the newsletter.

Thank you to Sheila Sykes, who stepped down from the management committee at last years AGM. Sheila had been a member since its inception and was responsible for an enormous amount of fundraising. She is still a fantastic supplier of cakes and is able to drum up a whole host of willing volunteers. A huge thank you Sheila!

As always, a very big thank you to our many supporters for their donations and sponsorship endeavours.

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