



Multiple Sclerosis Society
Northern Ireland

Foyle Branch FOCUS

Member Support & Services



Summer 2007

Shopmobility NOW AT FOYLESIDE SHOPPING CENTRE

Shopmobility is a service that provides scooters and wheelchairs, both manual and self-propelled and other walking aids to anyone who requires assistance to get around.

Equipment can be used overnight daily, weekly or monthly and is available for use in the shopping centre, around the city, for family occasions or holidays.

Training will be provided to ensure you are confident and safe using the equipment.

There is no charge for use of the equipment, though Shopmobility as a charitable organisation welcomes donations.

Shopmobility opening hours are, Monday to Friday 10.00 to 4.30 and Saturday 12.00 to 4.00.

It is possible to ring and book equipment for use outside of these hours.

The office and equipment is based at Foyleside Shopping Centre on the ground floor.

Tel: (028) 7136 8623

Email: shopmderry@btconnect.com

Address: Shopmobility Foyle, Level 1
Foyleside Shopping Centre
Orchard Street
L'Derry
BT48 6XY



Sandra Robinson, organiser and friends who last year organised a Sponsored Walk and a Dance in the Beaufort Hotel, Claudy to raise money for MS Society Foyle and Friends of Spruce. Sandra presents a cheque for £3,771.32 to Terry and Mary Crawford. Both charities were very grateful to Sandra and all involved.

QUIZ NIGHT



Wednesday May 30th 2007 saw another successful Quiz Night at the Waterfoot Hotel. Above we have quizmaster Maurice, ably assisted on the night by Damien. Below left: Bigfoot and the Hendersons who 'trampled' their way to victory and below Wesley's Rosboroughs who put up a strong challenge to emerge runners-up.



BRANCH SERVICES

The Foyle Branch of the MS Society delivers a range of services providing help and support to people living with and affected by MS, whilst funding research for hope in the future. Information and advice is available Monday to Friday from the Foyle Branch office, 58 Strand Road - Tel 7136 0831.

The MS Society Foyle Branch provide a range of services including: Physiotherapy exercise sessions, Yoga, Tai Chi/Qi Gong, Tuesday Club, Thursday Support Group, Accessible Transport, Library, Local and National Magazines.

For information on any of our services please telephone the MS Society Foyle Branch office on 7136 0831, e-mail: msfoyle@tiscali.co.uk or visit our website at www.msfoyle.org.uk

GOLDEN RAFFLE PRIZE WINNERS

- | | |
|-------------------|-------------------------------------------------------------------------------------------------------------|
| 1st Prize | £1,000 CASH
<i>Paul Doherty, Belfast</i> |
| 2nd Prize | Bycast Leather Armchair
<i>Liz Wilgar, Belfast</i> |
| 3rd Prize | 14" TV & DVD Player
<i>Ann Lamont, Portrush</i> |
| 4th Prize | 5 Day Return Ferry Crossing from Larne to Cairnryan
<i>Gerard Smyth, Lurgan</i> |
| 5th Prize | Hinari Coffee Makers & Supply of Coffee
<i>Bernard King, Belfast</i> |
| 6th Prize | Italy Replica Football Shirt & £30 voucher for Athletic Stores
<i>Stuart Rodgers, Lisburn</i> |
| 7th Prize | DAB Digital Radio
<i>Simon McConnell, Antrim</i> |
| 8th Prize | £50 Marks & Spencer Voucher
<i>N. McCrystal, Omagh</i> |
| 9th Prize | Alba CD Player
<i>L. Roberts, Antrim</i> |
| 10th Prize | Polaroid Instant Camera
<i>Wei Gno, Belfast</i> |

Who's Who

Development Officer: Terry McNamee

Tel: (028) 7136 0831

Welfare: Moira Leitch

Tel: (028) 7126 7400

Chairperson: Peter Eakin

Tel: (028) 7133 8641

Vice-Chair: Michael Heverin

Tel: (028) 7126 1118

Secretary: Marie McGinn

Tel: (028) 7186 0152

Treasurer: Damien McKenna

Tel: (028) 7136 3921

(MS Society Charity No: 207 495)



Pat Brown promotes the activities of MS Society Foyle

Pat Brown held a Ladies' Lunch at her home in May to promote the activities of the Foyle Branch of the MS Society. Pat felt that with the current ongoing internal difficulties within the MS Society and the effect this has had on fundraising, she wanted to assure people that the Foyle Branch was continuing to provide vital services to people affected by MS.

Fortunately it was a beautiful day and Pat was able to hold the lunch in her garden where everyone enjoyed the food, drinks and the lovely surroundings. The event was very well attended and the ladies generously donated a total of £520 to MS Society Foyle. A big thank you to Pat for all her hard work from all at the Foyle Branch.

NATALIZUMAB RE-APPROVED BY THE FDA

Science Daily - Just months after receiving FDA approval, Natalizumab, a medication for the treatment of multiple sclerosis (MS) and other inflammatory disorders, was voluntarily withdrawn by its manufacturers after three patients developed a brain infection known as Progressive Multifocal Leukoencephalopathy (PML). Natalizumab has recently been re-approved by the FDA, and a comprehensive article published in the latest issue of CNS Drug Reviews provides a timely overview of the drug, its pharmacological properties, clinical efficacy, safety and toxicology.

MS is a disorder that affects the nervous system, with leukocytes (inflammatory cells) attacking the body's neurons and causing serious damage. A highly effective immunosuppressive treatment, Natalizumab is an antibody that prevents leukocytes from crossing blood vessel walls into tissues such as the brain and spinal cord. The drug may also benefit secondary lymphoid organs, such as lymph nodes and the spleen, and

Testosterone may benefit Men with MS

A small study of 10 men with MS suggests that testosterone may have a beneficial effect for men with MS. The study, reported in Archives of Neurology, May 2007; vol 64: pp 683-688, was carried out by a team of researchers from the University of California at Los Angeles. They warned that the study was so small that further research is required before any general conclusions can be drawn. The fact that MS is much more common in women than men and evidence that MS often abates during pregnancy and that women with MS have lower levels of testosterone than those without all suggest a connection between hormone levels and MS. The men with an average age of 46 had MS for about 12 years on average. None was using disease modifying drugs. After a six-month observation period, the men applied a testosterone gel to their upper arms once daily for a year. This preliminary study found that testosterone treatment was associated with better scores on mental skills test and a 67% slowdown in loss of brain volume. The men's lean muscle mass also rose with testosterone treatment.

inhibit reactivation in the central nervous system. It has been shown to significantly reduce leukocyte cell numbers in spinal fluid, with benefits continuing for six months after treatment.

"The release of Natalizumab ushers in a new era in the treatment of MS," says Dr. Olaf Stüve, author of the study, noting, however, that while the short-term risk-benefit ratio appears positive, the long-term risks remain unknown. "As therapy with Natalizumab resumes worldwide, the neurologic community will garner more information about the long-term risks and benefits of this powerful therapeutic medication," but for now Natalizumab use is being strictly monitored. Both the FDA and TOUCH, a special distribution program designed to prevent patients not qualified for the treatment from receiving the drug, are working to make sure that any potential infectious complications are identified as early as possible.

CLIONA'S STORY

I have MS - MS doesn't have me!

My name is Cliona Evans. On 24th October 2005 I was diagnosed with relapsing and remitting MS at a private neurology clinic in Belfast.

I was making plans to go to university in the summer of 2004. I remember I began stumbling for no apparent reason and I had an overwhelming numbness sensation in both my legs and also pins and needles. I had no idea what was causing these various symptoms but I originally put the numbness down to poor circulation and tiredness. I remember originally experiencing what I now know were 'attacks' shortly after the birth of my daughter Jennifer-Ella in 2003. I would tire easily and suffer from some numbness and pins and needles. I thought all of these symptoms were just the result of my busy life style including being a new full time mum, combining breastfeeding and working part-time so I simply put my fatigue and all the strange symptoms down to the simple joys of motherhood!

In the summer of 2004 I thought it strange that I kept getting bouts of numbness in my legs and suffered from exhaustion that seemed to last anything from a few weeks to a month or more so I decided to visit my GP. The doctor I saw began to explain how numbness and pins and needles in the legs is usually an indication that someone is over-weight and that I should try to lose some weight. After losing a few pounds ironically the numbness cleared up and went away. It was such a relief. I had no reason to believe that it was something else and I could now relax and

get on with my life as a mother to Jennifer and wife to Rob.

Life went on and I decided to start driving lessons. Looking back I had quite a few of what I now know were 'relapses' during my driving lessons. I remember my feet being numb whilst I was out driving and I just thought again my circulation was poor and perhaps I had been holding my feet in the same position for too long. This numbness of both my feet cleared up after a few weeks and I thought nothing more of it until a few months later. A few weeks before I was due to take my practical driving test in July 2005, I developed a horrible numb sensation in my left hand and arm. I put it down to nerves and a friend suggested it could actually be a trapped nerve.

Thankfully I managed to ignore the numbness the best I could during my test and I was ecstatic when I passed first time round! Later that evening though my celebrations were cut short. I was at my sister's house when I noticed that my co-ordination was scarily out of control. I became really concerned about what was happening. A few nights later and my co-ordination was still out of sorts and the numbness in my left hand and arm began to spread to my chest and torso. I was really upset and my husband Rob agreed to take me to the hospital. I saw a doctor who did a few simple physical examinations. She asked me to touch my nose and then her finger and I just couldn't do it. My brain was registering what to do but my body was acting in such a strange way; it was as if it didn't belong to me. The doctor decided to take a few blood tests to rule out a viral infection. In the end, after failing a few more physical examinations she said she would refer me to see a neurologist, but warned me that the waiting time to see a neurologist in Derry was pretty long.

After many more visits to my GP complaining of persistent numbness and vision problems with my right eye she kindly agreed to refer me to see a neurologist privately (luckily through my husband's health care scheme we had medical insurance) and I saw Dr. J. Craig at the Ulster Independent clinic up in Belfast in September 2005. Within 4 weeks I had a physical examination, an MRI scan, blood tests and my MS diagnosis. It was so quick and I was so glad to know what was wrong with me.

At first the news didn't sink in and I remember going shopping in Belfast after Dr. Craig told me the news. To be honest I didn't really care about having MS. It just totally went over my head. My husband seemed more concerned than I was! We didn't really understand what it was and we were under the impression that I would receive treatment immediately and this would 'stop' my MS. We were in for a shock when the local MS nurse explained that I was once again on a waiting list to see an NHS neurologist who is the only person who can assess me

for and then prescribe the drug I needed. Then to be told that if I am eligible for the beta interferon drug treatment that I would once again be placed on another waiting list for the drug up to two years. My world came crashing down. Everything I was being told was incredibly negative and too much for me to digest. I wrote to my private neurologist and explained my plight and he kindly referred me to see an NHS neurologist he knew who worked in the City Hospital in Belfast. I saw Dr. McDonnell in December 2005 and he assessed me and said I was eligible for beta interferon injections but that the waiting list for this drug is two years.

I am now on the waiting list but it is hard to accept that the drug I so desperately need isn't currently available for me. I feel this is very cruel and I just wish there was some way I could get it right now. I know there are many other people in the same boat as me and it is just so unfair and really upsetting. My husband Rob and my little girl Jennifer keep me strong. I am keen to live a normal a life as possible and get on with things but when I'm being denied a drug that has been proven to help me I can't help but be a little bitter sometimes.

My outlook on life has definitely changed and although I get tired (often exhausted!) a lot more often now and I have had quite a few more relapses this year already I try to live every day to its full, and if not for me then for my little girl and her daddy. I want my daughter to have a normal and fun childhood and she won't be denied any of my energy. I still enjoy most of the things that I used to; like driving my gorgeous little car, going out with friends and going shopping when I'm feeling good and don't have a relapse that has too much of an impact on my life. I am still the same person and always will be. I am so thankful for people like Terry who is a fantastic ambassador for the MS Society Foyle branch. He keeps me right and has become a great friend. My motto for my life with MS is 'I have MS - MS doesn't have me!'

UPDATE - As you can see from the photo below my husband Rob and I had our second baby in April 2007. I have now started beta interferon injections and we have recently moved into a new bungalow.

