



Multiple Sclerosis Society  
Northern Ireland

# Foyle Branch ~ FOCUS ~

Member Support & Services



Spring/Summer 2005

## Charter Continence Care Roadshow 2005

The MS Society is working with Coloplast Limited to raise awareness and understanding of continence problems and how they might best be managed. The roadshow is a mobile information centre and will visit 46 cities across the UK over the next two months. The roadshow visits Scotland in early May and Northern Ireland in late May. Further details can be found on the Coloplast website at [www.coloplast.co.uk](http://www.coloplast.co.uk).

## CARERS AWARENESS WEEK

13th - 19th JUNE 2005

During Carers Awareness week a conference will be held in the City Hotel, Derry on Tuesday 14th June from 10.00am to 1.00pm with lunch provided.

The idea behind the conference is to celebrate Carers Awareness week and to bring carers together to look at the needs and issues affecting carers in the Foyle Trust area. A Foyle Carers Forum will also be launched which will help develop the provision of information, advice and support to carers. The Forum make up will include carers and relevant Foyle Trust staff.

If you provide support to enable someone to live independent in the community, come along to the conference and meet other Carers.

## CARING FOR CARERS

A Half-Day Conference

For all carers in the Foyle Trust area, whatever the age or disability of the person they are looking after.

For anyone who works with Carers

**Tuesday 14th June 2005**

Venue: City Hotel, Derry • 10am-1pm  
Incorporating the launch of  
Foyle Carers Forum

*Alana Kivlehan wins Derry Credit Union  
Limited Young People's Award 2005  
in the Carer Category*



Alana Kivlehan who is twelve years old has won the Derry Credit Union Young Carer's award. Alana lives with her parents Linda and Jim. Linda has Multiple Sclerosis and is dependant on Jim and Alana for help in the house. Alana often helps her Mammy, making her comfortable, removing her shoes, getting a cushion for her or making her favourite herbal tea and helping her in the bathroom.

On special occasions, before going out, Alana will help her Mammy with her make-up, nail varnish and jewellery. Some weekends Alana will go into town with her Mammy and actually take control of the electric wheelchair, manoeuvring through the busy shops.

Alana deserved this award because of the fantastic support she gives her Mammy and to let her know that both her Mammy and Daddy think they have been blessed with a very special daughter.

*Congratulations Alana from all at the MS Society Foyle Branch. The award was well and truly deserved.*

## 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](mailto:msfoyle@tiscali.co.uk) or visit our website at [www.msfoyle.freeserve.co.uk](http://www.msfoyle.freeserve.co.uk)**



### GOLDEN RAFFLE DRAW

The Draw was made on Monday 11th April and the Prizewinners were as follows:

**1st Prize: £1000 CASH**

- Mrs Bannerman, Hillsborough

**2nd Prize: Desktop Personal Computer**

- Anne Rice, Belfast

**3rd Prize: 14" TV & DVD Player**

- Liam Collins, Lisnaskea

**4th Prize: 4 Day Return Sailing to Scotland**

- Edmund McLaughlin, Larne

**5th Prize: Suite of Patio Furniture**

- K Hegarty, Ballycastle

**6th Prize: Giant Terraco Bicycle**

- Ian McBride, Comber

**7th Prize: CD Micro Music System**

- I. Lillie, Comber

**8th Prize: Outback Omega 200 Gas Grill BBQ**

- Kealan Sherry, Hilltown

**9th Prize: Day trip for 2 to Ikea**

- Petsie Baxter, Omagh

**10th Prize: Meal for 2 at The Stables, Groomsport**

- I. Greenlaw, Ballymoney.

*Thanks to all who purchased tickets or helped in any way with the Draw.*

## 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**

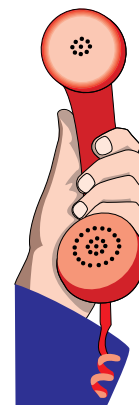
Secretary: Marie McGinn

**Tel: (028) 7186 0152**

Treasurer: Damien McKenna

**Tel: (028) 7136 3921**

**(MS Society Charity No: 207 495)**



## IN THE PRESS

In the past few weeks I have spoken to a variety of people suffering from a range of illnesses and to say they have had no affect on me would be wrong.

As a journalist I am well aware of the need to be impartial and my job is to report on the facts alone but sometimes this is easier said than done. I generally go home and leave my work behind at 5.30pm every day but when you put people behind the story, it is hard.

Just this month alone, I have been affected in some way or another by Eimear, who suffers from MS and whose life changed overnight; by Jack, who continues to stay positive despite living with Parkinson's; and Judy, who felt 'useless' before realising that what she had was depression.

Three so very different people all coping in their own way. But they all had one similarity: they were surviving through positive thinking. An attitude that continues to astound me.

A few years ago, after watching a televised report on how to check for breast lumps, I discovered an abnormality myself and I have to say it scared me to the core. It was a long week waiting to get an appointment and I have never breathed easier when the doctor declared, 'It's all grand. Nothing to be worrying about'.

But it so easily could have gone the other way. And if I'm honest I'm not sure I would

have been as positive as those I have just mentioned. I know you never know how you will cope until it happens to you but I feel so thankful that I've never had to find out.

All the above mentioned illnesses can happen to anyone at any time. That's what affects me so much. The absolute uncertainty of life.

But then I suppose you have to learn to cope. It would be so easy for Eimear, Jack or Judy to bury their heads in the sand and live in a bubble of their own. But that would be futile and non-conducive to leading a full life - which, by the way, is entirely possible if each illness is managed on its own merits.

Life throws all sorts of trials and tribulations at you, that's just the way of it, but it's accepting this that makes them easier to deal with. I only hope I never have to find out.

*Extract from Sunday Journal - 24th April 2005*

## RESEARCH

### Cooling therapy for tremor?

It is estimated that tremor affects more than 50% of all people with MS. Tremor, particularly "intention tremor" which occurs when someone reaches for something, can be very disabling and can impact on daily activities. Drug therapies and physical treatments, such as adding weights to the arms, have been shown to be only partially effective. Therefore, this study investigated whether cooling the forearms of people with MS would have a beneficial effect on intention tremor.

29 people with moderate MS and intention tremor took part in the study. 18 received "deep cooling" of the forearm (to 15-18°C) and 11 received "moderate cooling" (to 22-25°C). This was in the form of a wrap containing cooling liquid (similar to a blood pressure cuff) applied for 15 minutes. In some cases, both arms of participants were used. A task involving finger tapping as many times as possible and a task involving moving a cursor between two targets as quickly and accurately as possible (the target task) were administered. Assessments were made before cooling, immediately after and then at ten-minute intervals up to 30 minutes after cooling.

The cooling was well tolerated by the participants, with no side effects. Core body temperature and heart rate were not affected.

After cooling, the speed and accuracy of both tasks was adversely affected, although this returned to pre-cooling levels after ten minutes. Both levels of cooling reduced the size of the tremor, although this effect appeared greater after deep cooling than moderate cooling, as measured by additional movements made on the target task.

Further analysis showed that the rate at which messages passed along the nerves to the hands and arms was reduced after cooling, accounting for the reduced tremor. The authors therefore suggest that the reduction in tremor may be the result of reduced muscle activity.

The results of this study indicate that cooling of limbs can reduce intention tremor in MS. The authors suggest that cooling the arms before undertaking daily activities such as writing or eating may be useful. They do note however that it is unclear whether people with more severe tremor would benefit from cooling in this way.

*This report was published in the Journal of Neurology, Neurosurgery and Psychiatry, 2004. Vol. 76, pages 373-379.*

### A clinical trial of pirfenidone in secondary progressive MS

A proportion of people with relapsing remitting MS (RRMS) will go on to develop secondary progressive MS (SPMS). SPMS is characterised by progressive disability, with or without superimposed relapses. The biological mechanisms behind the development of SPMS are not fully understood, although a type of signalling molecule called TNF-alpha has been implicated in this progression. This clinical trial evaluated the effect of drug called pirfenidone, which is thought to reduce levels of TNF-alpha in people with SPMS.

43 people with moderate to severe SPMS took part in the study. Participants were randomly allocated to receive either pirfenidone (25 people) or placebo (18 people), a control substance known to cause no effect). Pirfenidone was given in the form of an oral tablet, daily. All participants were monitored for a period of 12 months with clinical examinations initially and one, three, six, nine and 12 months after the start of the study. MRI scans

to visualise MS-related damage in the brain and spinal cord were performed initially and at the middle and end of the study period. The study was also "double blind" i.e. neither the investigators or the participants knew who received which treatment.

Results showed that those people taking pirfenidone had a significant improvement in "neurological function", evident one month after treatment started and continuing for the 12-month period. There was no change seen in the group taking the placebo. During the study only two of the pirfenidone group experienced relapses, compared to five of the placebo group. Participants taking pirfenidone also experienced significant improvement in bladder problems, compared to those receiving placebo. MRI results, however, showed no differences between the two groups.

Seven people from the placebo group dropped out of the study because of continued disability progression. Nine participants receiving pirfenidone discontinued, three due to side effects, three because of a lack of a beneficial effect and three for other reasons.

The results from this study, which was sponsored by the pharmaceutical company which produce pirfenidone, indicates that this drug appears to have a beneficial impact on secondary, progressive MS. The number of study participants is small, but the authors conclude that a larger study could help to clarify the effect of pirfenidone on SPMS.

*This report was published in Multiple Sclerosis, 2004. Vol. 11, pages 149-158.*

## QUIZ NIGHT

What a great night the quiz turned out to be. There was a brilliant turnout with nine teams competing for a bitterly contested prize. The quiz master Maurice was his usual witty self, ably supported by Damian and Katie.

The raffle prizes, donated by the many kind well-wishers, and mainly organised by Caitriona Cunningham and Marie Henderson were greatly appreciated.

The winning team, the Cunningham Clan aided and abetted by Etna were the winners on the night.

Our thanks to everyone who attended for making the night such a success. As usual we are indebted to Maurice, Damian and Katie for making the night so enjoyable.

