



Multiple Sclerosis Society
Northern Ireland

Foyle Branch FOCUS

Member Support & Services



Autumn 2005



TAKE TITAN'S CHALLENGE

BBC presenter Donna Traynor and Titan the Tiger are joined by Bernadette Lafferty and Terry McNamee, schools link officers of the Foyle Branch of the MS Society Northern Ireland at the launch of Titan's Leaps and Bounds Champion Challenge.

The MS Society Northern Ireland is now hoping that primary schools in the Foyle Branch area will be ready and roaring to accept Titan's challenge.

Commenting on behalf of the Foyle Branch, Terry McNamee said, "We believe we have developed a programme which will capture the imagination of children across Northern Ireland whilst being teacher friendly and fitting in with the school curriculum. We hope that they will be willing to lend us their much valued and much needed support. Titan's Leaps and Bounds Champion Challenge is an awareness fundraising programme aimed at encouraging primary school children to engage in some form of sponsored physical activity i.e dancing, swimming, skipping etc".

If you are interested in finding out more about how to become involved in Titan's Leaps and Bounds Champion Challenge, please contact the Foyle Branch of the MS Society Northern Ireland on (028) 7136 0831.

Tom Leen, a native of Tralee, County Kerry (pictured below with his daughter Mary), has lived in the United States since he left his native soil in 1955.

Tom lived in Minnesota where there was a high rate of MS among young people. Every year for the past 10 years Tom has taken to the saddle, in a four day, 150 mile daily cycle for the MS Society of America.

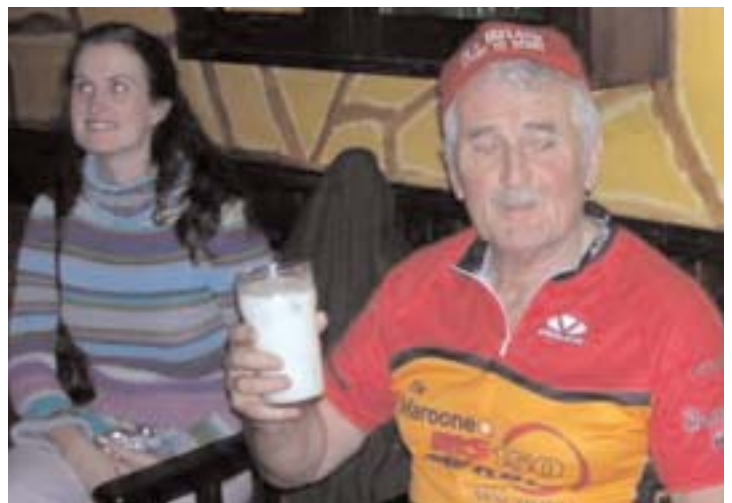
Having met up with Terry McNamee, Development Officer with the MS Society Foyle Branch in 2002, Tom wanted to return to Ireland and help raise money for the Foyle Branch.

Tom left Tralee, Co. Kerry on Friday 16th September arriving in Derry at 10.30pm on the 17th. This is a wonderful gesture from Tom whose commitment to raising funds for people with MS is an example to all of us.

A total of £1,500 was raised in 2004 for Tom's sponsored cycle and we hope to exceed that amount this year.

Contact Terry on 7136 0831 - and remember, every little helps.

73 year old undertakes a gruelling 48 hour, 302 mile cycle ride from Kerry to Derry!



Tom Leen enjoys a well-earned pint of milk in the Iona House Bar after completing his epic Kerry to Derry 2005 cycle ride in aid of MS Foyle Branch.

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.freeseerve.co.uk

~ CHARITY GOLF TOURNAMENT ~



Nelson McGonagle takes time out of his busy schedule organising the Roe Park Charity golf tournament to be photographed with Marie, Eimear and Terry. What a fantastic day. Over two hundred people played golf and with sponsorship and raffle tickets a total of £8,500 was raised. This was divided equally between Limegrove School and MS Foyle. Nelson, thank you very much and Geoff and Priscilla Miller who worked so hard to ensure the day was a success. We wish you good luck in the future Nelson with your annual charity golf fundraiser.

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)



GETTING TO KNOW YOU!

Moira Leitch is Support Officer of the MS Society Foyle Branch. After being diagnosed with MS in 1992, Moira joined the MS Society and has been involved with the Foyle Branch ever since.



Married to Des they have two children, Claire 27 and Karen 23. Moira is an avid reader and also likes to relax by doing Tai Chi and Yoga which she has been practising for the past ten years.

Happiest childhood memory?

Family holiday in Donegal

Human quality you most admire?

Honesty and sincerity

Human quality you least admire? *Arrogance*

Favourite book?

The Mayor of Casterbridge by Thomas Hardy

Favourite film?

The Usual Suspects with Kevin Spacey

Favourite television programme?

The Bill and Casualty

Favourite food/drink?

Indian cuisine and red wine, but not together

Favourite holiday destination? *Tenerife*

What is your greatest fear? *Losing my family*

You've won the lottery, what would you do?

Tell no-one

How would you like to be remembered?

As someone who listened and cared.

RESEARCH

Positive results from Sativex pain trial

The cannabis based medicine, Sativex, is effective in reducing central neuropathic pain and sleep disturbance in people with MS according to a study published in the journal 'Neurology'.

This randomised, controlled trial in 66 patients showed the drug was significantly superior to placebo. Sixty-five per cent of those taking part needed support to walk or were wheelchair users. They suffered from moderate to severe central neuropathic pain which had not been alleviated by currently available medications. Patients continued to take their existing medication throughout the trial. Sativex was administered as an oral spray, allowing flexible dosing suited to the variable nature of MS.

Dr Carolyn Young, the principal investigator and consultant neurologist at the Walton Centre for Neurology and Neurosurgery in Liverpool, said, "Central neuropathic pain occurs frequently in people with MS. It can be tremendously debilitating and unresponsive to existing therapies. Our findings demonstrate that Sativex was effective in reducing both central pain in MS and pain-related sleep disturbance in a population with moderate to severe central pain inadequately relieved by existing medication."

New approval sought for Tysabri



Elan Corporation and Biogen Idec have made a priority review application to the US Food and Drug Administration (FDA) for Tysabri (natalizumab) to be made available again for the treatment of multiple sclerosis.

Their submission includes final two-year data from trials of the drug as a monotherapy and in combination with the beta interferon Avonex, a

safety assessment and a plan for monitoring risk.

If priority is granted, the FDA would make its decision in around six months. The companies will submit similar data to the European Medicines Agency (EMA).

Burt Adelman, Biogen executive vice president, said, "We are grateful to the MS community for their patience and support over the last several months while we've conducted an extensive safety evaluation of Tysabri in collaboration with leading experts. We look forward to working with regulatory authorities during the review process, and ultimately we hope to provide Tysabri to people living with MS, a disease with significant unmet need."

Lars Ekman, Elan executive vice president, added "We are committed to working closely with regulatory authorities to define a path forward for Tysabri as a treatment choice for patients who struggle with the debilitating effects of the disease."

In February, Biogen Idec and Elan announced that they had voluntarily suspended the drug from the US market and all ongoing clinical trials based on reports of progressive multifocal leukoencephalopathy (PML), a rare and potentially fatal, demyelinating disease of the central nervous system. A comprehensive safety evaluation was launched.

• Phone therapy works •

Psychotherapy over the telephone reduces symptoms of depression in people disabled by MS, researchers at the University of California have found. "The biggest advantage is that it overcomes barriers," Dr David C. Mohr told Reuters. "Even in urban areas where mental health care is available, there are a lot of barriers, such as physical disabilities, time constraints, transportation problems or not being able to get away from home because of child care or elder care duties."

The researchers recruited 127 patients with depression and functional impairments due to MS who agreed to psychotherapy delivered over the telephone. They were randomly assigned to treatment with cognitive behavioural therapy or supportive emotion-focused therapy, both in 16 weekly 50-minute sessions.

According to the researchers' report in the Archives

of General Psychiatry, the prevalence of major depression dropped from 73 per cent to 13 per cent in the cognitive behavioural therapy group and 69 per cent in the supportive emotion-focused group.

Dr. Mohr said there was also an 'extraordinarily low attrition rate, with only 5 per cent who dropped out. In most clinical trials of treatment for depression 15 per cent to 60 per cent drop out over 16 weeks.'

He said telephone-administered therapy worked because patients 'clearly appear to become very attached and very bonded to their therapists. Part of the reason is that a lot of the non-verbal information about how people feel is carried through the voice. There's a way in which the emotions people are feeling or the empathy that the therapist might be expressing comes through. Based on our results, we can say that it is possible to deliver quality care over the phone but the question that is still outstanding is whether it is equivalent to face-to-face care.'



Pictured are Fiona Bryce, Steven Brown and Jake Desmond, from Muff Scouts Group who were extremely busy packing bags at Sainsbury's Meadowbank on Friday and Saturday 7th/8th October. Muff Scouts Group very kindly donated £650 from this fundraising event to the MS Society Foyle Branch. We are extremely grateful and wish all involved all the best for the future.



The MS Society's Shining Star is presented to Nancy Warnock by branch secretary Marie and committee member Raymond to mark her retirement from the committee after 40 years of outstanding service to the MS Society Foyle Branch.

IN THE PRESS

SCOOTERING TO ROMANCE

When Sylvie Brown decided she wanted more action in her life, she went shopping for a mobility scooter. But, as she told Bella, she got more than she bargained for ...

'Most girls of my age were letting their hair down at parties on Friday night but I was stuck at home, crawling across the floor on my hands and knee. "Why don't you admit you need a wheelchair?" asked my brother. "No way," I said "I'm fine like this." I was 23 years old and had been suffering from MS for two years. I could only walk short distances with the help of a stick but I hated thinking of myself as ill.'

One day she had the idea that if she did something spectacular people would think about her as someone with a sense of adventure rather than someone suffering from MS. So she did a tandem skydive for charity. Everyone was amazed and she had letters and phone calls from old friends. One had a suggestion.

"You should get yourself one of those mobility scooters," he told me. "Then you'll be able to get around a lot more easily. My uncle sells them. Here's his phone number." Another friend said, "That's a great idea. You'll get out and about, feel the wind in your hair. You might even meet Mr Right."

"I hope so," I said. A few days later, as I struggled up my path, I stopped. There was a hunky man on my doorstep - Steve, the scooter salesman. He showed me how it worked. I signed on the dotted line and within weeks I had my shiny new machine. I whizzed about on it.

'But it soon started playing up. I phoned Steve and he came straight over. It happened time and time again and on each occasion Steve stayed a little longer. We became friends. But he was in his forties - a lot older than me. "He's just being kind," I told my friends. "He doesn't fancy me." But I was wrong and soon our friendship blossomed into something very special. Now five years on we're still head over heels in love. My scooter did indeed lead me to my Mr Right.'