



Multiple Sclerosis Society
Northern Ireland

Foyle Branch ~ **FOCUS** ~

Member Support & Services



SUMMER 2004

WE NEED YOUR HELP!

Kerry to Derry Sponsored Cycle

Yes that man is back again! Our friend from America, Tom Leen is leaving Kerry on Friday 3rd of September to cycle the 302 miles to Derry. Tom will arrive in Derry the following evening, Saturday the 4th of September.

Tom, 72 years old has raised 1000's of dollars for people affected by MS in America. Tom needs your help to make his effort worthwhile.

A Sponsorship Form is available at the back of this Newsletter to cut out and use. Please support Tom's lovely gesture towards people in this area. Telephone (028) 7136 0831 for more information.



BRING & BUY SALE A GREAT SUCCESS!

Nancy, Kathleen, Margaret and Maynard pictured at the Bring and Buy Sale held on May 14th in the Waterside Presbyterian Church Hall. A total of £566 was raised for the Foyle Branch. Thanks to all who helped Nancy and Margaret make this evening such a success.



• DATE FOR YOUR DIARY •

The next Thursday Support Group meeting will be held on Thursday 9th September 2004 at Foyle Disability Resource Centre (Glenbrook) at 7.30pm.

Note: This is the second Thursday in September.

Check out our Website!
www.msfoyle.freeserve.co.uk



*Foyle MS Society
Branch members enjoy the home cooking
which was available at the recent
Bring and Buy Sale*

Getting To Know You!

As Vice-chair of the MS Society Foyle Branch and Chair of Bridge Accessible Transport, Michael Heverin certainly likes to keep himself busy.



Michael Heverin

Michael was born in Liverpool, March 1946 and was brought up in Strabane, Co. Tyrone. Attending Queens University, he qualified as an architect in 1970. His active career spanned 32 years, 27 with the Northern Ireland Housing Executive of which 24 were in the Derry area.

Michael's hobbies included skin diving, fly fishing and reading. Michael and his younger sister, Josephine have both been diagnosed with Multiple Sclerosis.

Happiest childhood memory?

Fishing on the river Mourne and catching my first fish, a three-quarter pound brown trout.

Human quality you most admire? Honesty.

Human quality you least admire? Greed.

Favourite book? Pillars of Hercules - Paul Theroux.

Favourite film? Draughtsman's Contract - Peter Greenaway.

Favourite television programme? Restoration

Favourite food/drink? Sea trout with almonds, red wine.

Favourite holiday destination? Morocco.

What is your greatest fear? World War Three.

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

See my family ok and give the rest to charity.

How would you like to be remembered?

Having made a positive contribution in life.

• REMEMBER •

The N.I. Mag and this Branch news-sheet can also be provided on cassette tape. Please contact the Branch office for more details on (028) 7136 0831

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)



MS
SOCIETY
N.I.



FOYLE
BRANCH

Check out our Website!

www.msfoyle.freemove.co.uk

OMAGH HALF-MARATHON Fund-raising



Pauline Breslin pictured receiving a cheque on behalf of the Foyle Branch from Mickey and Brian who completed the Omagh Half-Marathon. Mickey, Brian and friends collected sponsorship totalling £375

Health and Social Care Services

MS Specialist Nurse

Fiona Mullan our MS Specialist Nurse is based at Altnagelvin Hospital and provides information, advice and support to people affected by MS. Fiona also deals with disease modifying therapies.



Contact: Fiona Mullan - Tel: (028) 7129 6132

Note: If Fiona is out, please leave your name and a contact telephone number.

Continence Services

Based at Rectory Field and provides-

- Specialist toilet aids and appliances
- Continence reusable/disposable products and other specialist equipment to enable people to live full and independent lives
- Education and training programmes
- General advice and literature

Contact: Referral by your Consultant, GP, MS Nurse or other Healthcare worker.

Social Work Services

Social work services include advice, carer assessments, counselling and developing care plans that include services such as home help, domiciliary care, day care and respite care.

Contact: Self-referral or your Healthcare worker.

Physical Disability Team - (028) 7135 4031

Sensory Disability Team - (028) 7137 4619

Occupational Therapy

The Occupational Therapy Service helps people to reach their maximum level of function and independence with daily living. Following assessment, needs identified within areas of the home environment; personal care; employment; leisure and interpersonal relationships may be addressed.

Contact: Referral by your Consultant, GP or other Healthcare worker.

Physiotherapy

Physiotherapy uses assessment, diagnosis and treatment to maximise the person's level of independence, mobility and to relieve pain.

Contact: Referral by your Consultant, GP or other healthcare worker.

Sensory Support Services

The Sensory Support Service provides a comprehensive range of services to people with significant sight and/or hearing loss. Full assessment of need and advice on aids and equipment is available at their office, 16 Bishop Street, Derry.

Contact: Tel: (028) 7137 4619

Podiatry

Podiatrists are devoted to the study and treatment of disorders of the foot and ankle. The human foot is a complex structure and podiatrists treat corns, calluses, ingrown nails, bunions, heel spurs and arch problems as well as foot problems related to diabetes and rheumatoid arthritis.

Contact: Referral by your Consultant, GP or other Healthcare worker.

Speech and Language Therapy

This service helps clients with communication/swallowing difficulties through formal and informal assessment, diagnosis and treatment.

Contact: referral by your Consultant, GP or other Healthcare worker.

Nutrition and Dietetics

This service aims to educate people in making the correct food choices necessary in the management of their condition and promotes a healthy attitude towards nutrition.

Contact: Referral by your Consultant, GP or other Healthcare worker.

Tissue Viability Nurse

The role of the Tissue Viability Nurse Specialist is to promote 'best practice' in the prevention and management of tissue damage, e.g. pressure ulceration. This will be achieved by working collaboratively with the multi-disciplinary team, to provide patients and staff in Foyle Health and Social Services Trust with specialist advice, education and clinical support in all aspects of wound care and prevention of tissue damage. The Foyle Trust Tissue Viability Nurse is Frances Curry.

Contact: Referral by your Consultant, GP or other Healthcare worker.

This list is not exhaustive and other help may be available. Please discuss any problems with your Consultant, GP or MS Nurse.

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 (028) 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 (028) 7136 0831, e-mail: msfoyle@tiscali.co.uk or visit our website at www.msfoyle.freeserve.co.uk



Flexible Key to Caring

With Tony Blair agreeing that the UK's six million carers should be given the chance to work part-time, Tony Campbell welcomed the opportunity to tell him how much it mattered when they met at a Government 'Big Conversation' event in Downing Street.

Tony, who is 61, lives near Winchester and told BBC News Online why carers need flexible hours. "I have been caring for my wife Susan since she was diagnosed with Multiple Sclerosis 19 years ago, which left her in a wheelchair and incontinent with no control over her muscles. I use a hoist to lift her out of bed or up from an armchair".

"I also work as a customer service advisor at a British Gas call centre in Southampton, which I do as a break from the repetition of staying at home and caring for Susan as much as for the money. I need to see other people and working in a team and getting out helps me in my relationship with Susan.

"Although two social workers visit her twice a day, each for an hour and half, all my time at home is spent looking after my wife. I get her up in the morning, give her breakfast, wash her and care for her on a full-time basis at the weekend. At night I get five or six hours sleep.

"Until recently I was working a full week Monday to Friday, 9.30am until 6pm, and every other Saturday I had to do a half day. I wasn't getting enough sleep, any time to myself to do normal things around the house like looking after the garden and I wasn't spending any quality leisure time with Susan either.

"British Gas have a carers' policy that allows me to achieve the right work-life balance and now I work a three-day week, Monday to Wednesday, and one Saturday in eight - but I get a day off in lieu. The

scheme also means that carers who take a day's holiday only use half a day from their annual leave.

"A carers' policy based around flexible hours must be made law so it can be incorporated into a contract of employment, and companies should be aware of their responsibility to make it clear to workers that the option is available. With people living longer there are going to be more carers in the future but people will still have to work beyond retirement age. We should prepare for this."

research

Supporting people with MS at Diagnosis

Receiving a diagnosis of MS has a severe emotional impact on people. Traditionally, diagnosis has centred around the neurologist giving the diagnosis, and then answering questions from the patient. However, with limited time this is often unsatisfactory for both parties. A large Canadian MS clinic has used a new model of providing psycho-social support at the time of diagnosis - a mental health practitioner working in tandem with the diagnosing neurologist in order to increase the level of patient care.

The report highlights the need for the diagnosing neurologist to consider the patients' personality type and emotional make-up, to determine how best to deliver the diagnosis. Finding out what the patient wants and why (e.g. to wait for a firm diagnosis, or receive written information), and providing follow up support afterwards can give the patient time to come to terms with the diagnosis.

The authors suggest that wherever possible the patient should bring a family member or friend with them to the meeting - neurologists should deliver the diagnosis clearly and concisely in a private area. It is recognised that patients may well not "hear" much of what is being said to them and they should be reassured that they will have the opportunity to speak to the neurologist again.

After diagnosis, it is suggested that patients are transferred to a mental health practitioner - called a Clinic Co-ordinator in the Canadian clinic, to reduce any perceived stigma associated with seeing a counsellor.

This report recommends that all newly diagnosed people should be given printed practical information on MS, a contact number for the Clinic Co-ordinator or MS-specialist nurse, information about the MS Society and provided with reassurance regarding access to care and follow-up contact. The report stresses the importance of a follow-up telephone call a week after diagnosis.

This model is a multi-disciplinary approach to managing the diagnosis of MS, in order to optimise the process for the patient. The goal of the diagnostic process should not be patient acceptance of the diagnosis, but reassurance that good quality of life is attainable. Similarly, provision of the necessary support is applicable at all stages of MS and is part of the process in helping the person with MS to live with the diagnosis.

*This report was published in The
International MS Journal, 2004. Vol. 11,
pages 3-9.*

Did you know?

If you are a disabled person who has difficulty using the phone book for any reason - physical impairment, visual impairment etc, you are entitled to free directory enquiry services. All telephone companies must provide this - just dial 195 to register. This normally involves a form, which must be signed by someone acceptable to the telephone company, such as your doctor. You will receive a personal identification number, which you will need to quote when using the service. You should not have to pay for directory enquiries again even when using your mobile phone.

*For further information, please contact Terry at the
office - (028) 7136 0831*

Assessment of Disability in People with Multiple Sclerosis

We have recently completed a study (soon to be published in the journal "Multiple Sclerosis") and thought we would take this opportunity to share the results with you.

As MS is usually diagnosed between the ages of 20 and 40 years, people may be living with some degree of disability for quite a long time, as MS is not thought to affect life expectancy. Therefore, we need to be able to assess the level of disability that people with MS experience in order to provide the most appropriate care and to effectively manage symptoms.

Some questionnaires that are used to assess disability ask about what we call 'activities of daily living'. These activities include eating meals, using stairs, moving from bed into a chair, walking ability, grooming (activities such as brushing your teeth, or brushing your hair), bowel and bladder function, using the toilet, bathing or showering, and getting dressed. A commonly used questionnaire that assesses these activities of daily living is the Barthel Index. This questionnaire was originally developed for use in a hospital setting (i.e. for in-patients), therefore there has been some concern about how effective it is when assessing a person's disability in their own home.

To address this concern, another questionnaire was developed called the Community Dependency Index. This questionnaire has very similar questions to the Barthel Index, but it has been adapted slightly to take the home environment into consideration. The researchers who designed the Community Dependency Index thought that it might be more suitable for assessing a person's disability at home (i.e. in the community).

We therefore decided to use both of these questionnaires to assess 90 people with MS as part of an ongoing study, and then compare them to see if there were any differences in how they assess a person's disability. We found that there were no important differences between the two questionnaires as both of them produced very similar results and they were equally good at

measuring disability in a community setting.

Therefore, since it would appear that the majority of clinicians and researchers commonly use the Barthel Index, we have suggested that perhaps this questionnaire should continue to be used.

If you would like more information about this research, or any other research ongoing at the University of Ulster, please do not hesitate to contact us at the details below.

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~ Multiple Sclerosis and Bladder Problems: Study Update ~

Between March 2003 and May 2004 we undertook a Pilot Study to investigate the benefits of various physio-therapeutic techniques on bladder problems in people with multiple sclerosis.

The preliminary results of this study have suggested that these techniques may be of benefit to some people with MS and we have therefore decided to undertake a larger study to look at this more closely. Recruitment of participants, (under strict inclusion/exclusion criteria), for this study has recently commenced. Since completing the pilot study we have established a number of treatment clinics throughout Northern Ireland, which hopefully will make travel easier for participants.

If you are interested in taking part or would like more information, please do not hesitate to contact me at the details provided below.

Our sincere thanks to all those who expressed

an interest in taking part and to those who participated. We would also like to take this opportunity to acknowledge the help of those who facilitated the study.

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Multiple Sclerosis and Vitamin D

In February and March of this year we conducted a pilot study to look at the levels of vitamin D in blood samples of people with multiple sclerosis (MS), and to compare them to levels in people who do not have MS.

I would like to thank all those who expressed an interest in taking part, those who participated, and also acknowledge the help of those who facilitated the study. Your interest and enthusiasm was much appreciated.

The preliminary results to date from our study suggest that adults living in Northern Ireland, both those diagnosed with MS and those without the disease, have very low vitamin D levels in their blood in wintertime. We know that this may be due to the lack of sunshine at this time of the year which is needed to make vitamin D in our bodies, but we do not yet know whether this low vitamin D concentration explains why some people develop MS. Therefore, we plan to continue our research in this important area in order to get a better picture of the role of vitamin D in MS.

Many thanks once again to all those who took part in this study. If you would like more information on this or any other studies ongoing at the University of Ulster, please do not hesitate to contact us at the details provided below.

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Marie McGinn writes ...

While collecting on our flag day in April, I was approached by a young lady who asked if I knew anyone in our MS Foyle Branch who had Trigeminal Neuralgia (TN). Having been diagnosed with TN herself, although she does not have MS, her Neurologist informs her that this can be a symptom of MS.

Having spent time on the internet getting details on TN, she would love to chat to someone locally who understands the condition. I think at some time we all know what it is like to feel alone. If you know of anyone who can help, please contact the MS Office. Tel. (028) 7136 0831

Note: TN is typically described as extremely severe episodes of pain and possible the most painful condition known to mankind. Stabbing, periodic pain as if electric shock is given to some points on the face.



Thanks!

Thanks to Louise and friends for participating in the Belfast Marathon and raising a total of £675 for the Foyle Branch of MS Society



M.S. SOCIETY - FOYLE BRANCH



Tom Leen's Sponsored Cycle 2004

Leaving Kerry: Fri. 3rd Sept. ~ Arriving Derry: Sat. 4th Sept.

~ Sponsorship Form ~

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Cycle undertaken in aid of M.S. Society Foyle Branch

Registered Charity No: 207495

Tel: (028) 7136 0831