



MS

news

THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

085
Spring 2009

JOINING THE DOTS

A look at the world
of MS research



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10th Annual General Meeting

(49th AGM since the MS Society's foundation)



Dear member,

In an effort to reduce costs, the call for motions and board nominations are advertised in this issue of 'MSnews' (below). The AGM legal notice and voting papers will be sent to each member along with the next issue of 'MSnews', out in the summer.

Notice is hereby given that the 10th Annual General Meeting of the Multiple Sclerosis Society of Ireland will take place in the Clayton Hotel, Ballybrit, Co Galway on Sunday, 27 September at 11am.

The results of the postal vote for the board vacancies and motions, if any, plus the council's nomination to the board, will be announced at the AGM.

The procedures for motions and board nominations are listed hereunder.

Every registered member is entitled to a postal vote. Voting papers will be posted to all registered members three weeks prior to the AGM and must be returned to National Office, 80 Northumberland Rd, Dublin 4 by Friday, 18 September 2009.

Anne Winslow
Company Secretary

MOTIONS

Any member or Branch may forward a motion to the Standing Orders Committee so that these can be clarified legally and their suitability for an AGM confirmed.

Operational motions should be sent to the Chief Executive or Chairman only for decision by the Board.
Closing date for receipt of motions is Friday, 21 August 2009.

INTERESTED IN BEING A BOARD MEMBER?

Members, Branches, Council, the Board and Staff may propose candidates for inclusion on a panel, from which a nominating committee will select those to go forward for election for Board membership. All nominations must be proposed and seconded by members.

The Nominating Committee will take into account the range of skills necessary for Board membership and where possible, geographical spread and gender balance and the experience and qualifications of the candidates.

The Nominating Committee will evaluate candidates (new and those seeking re-election) as to their suitability prior to putting their recommendations to the

overall membership for ratification in a postal vote. Further details and nomination forms are available on the website: www.ms-society.ie.

Closing date for receipt of nomination forms for the incoming Board is Friday, 21 August 2009.

MS IRELAND'S 2009 ANNUAL AWARDS

The nominations for this year's Annual Awards are now open and we invite Branches and individual members to nominate members who they feel deserve recognition. Our Annual Awards are the Society's way of recognising the contribution many of our members make within their families, local communities and MS Ireland.

There are three awards and the categories are:

- **MS Person of the Year**
- **MS Carer/Helper of the Year**
- **MS Volunteer of the Year.**

Full details and nomination forms are available on the website. The closing date for receipt of nomination forms is Friday, 17 July 2009.

The annual awards for 2009 will be presented at the Annual Conference in September.

DEAR READER

The current economic climate is on all our minds and in MS Ireland we are unfortunately faced with some tough times. Our statutory funding has been reduced significantly this year and trends are already proving that income from fundraising is decreasing. Now more than ever, I encourage you to keep supporting MS Ireland. Our members, friends and supporters have always been generous with their time and money and we hope this generosity continues so we can maintain the services we deliver all over the country.

The recession may provide us with challenges but it also provides us with many opportunities. It will allow us to refocus on the main business of MS Ireland. We have many services and resources that are highly valued by the MS community and we want to ensure that these continue to meet needs. I have no doubt we can do this by rolling up our sleeves and working together. It is important for MS Ireland that staff, volunteers, allied organisations, health professionals and other interested groups and stakeholders work as a team in an effort to always enable and empower people affected by MS to live the life of their choice to their full potential.

MS Ireland is a busy organisation and I just want to highlight some of the work that is ongoing:



- The preliminary results from the 'Getting the Balance Right' research programme look very promising and excellent reports are coming back from those who are taking part on the physical therapy/exercise programme
- There are some new developments in the Care Centre that can help residents with the continued management of their MS beyond their stay in the centre (see page 24)
- Our research programme was reactivated last year and we are delighted to be supporting two research projects (see page 10)
- Our new website was launched at the end of last year and I would encourage you to visit it regularly to keep up to date with developments in MS and MS Ireland: www.ms-society.ie.

In this edition of 'MSnews' you will find two raffle ticket booklets. I gratefully ask each of you to sell these tickets to your friends and family. Your support is very much appreciated.

Warm regards,

ANNE WINSLOW
Chief Executive, MS Ireland



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NEWSFLASH!

DIARY DATE: Wednesday, 27 May 2009 is the first International MS Day. Awareness events and activities will take place all over the world. Check out our website, www.ms-society.ie, in early April for more details. Be part of the global MS movement!

Disclaimer: 'MSnews' is the magazine of MS Ireland. It exists to foster informed debate and comment about all issues relating to MS. The view of contributors are not necessarily those of the Society. No treatments or therapies should be attempted or products used without qualified medical or professional advice.

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Stephen Keogh, left, and Felipe Contepomi pose with Natasha Duffy of MS Walks during the launch of the Walks 2009 event calendar

Leinster Rugby supports MS Ireland

RUGBY SUPREMOS Stephen Keogh and Felipe Contepomi have been unveiled as MS Ireland's Leinster Rugby ambassadors for 2009. As part of the club's charity adoption programme Stephen and Felipe will become friends of the Society and help to support its work.

Stephen, who plays on the back row and had four caps for Ireland, said: "We are delighted that MS Ireland is Leinster Rugby's charity of the year."

Felipe, who is a fly half/centre and originally from Argentina, said: "MS is a condition that affects the whole family and we are delighted to be able to lend our support to this very worthwhile cause."

MS Ireland would like to thank Stephen and Felipe for their support and look forward to a fruitful year ahead.

NEW MS IRELAND WEBSITE GOES LIVE

THE NEW MS Ireland website, www.ms-society.ie, has gone live. After much work and commitment the staff at the society launched the new look website late last year. The results have been outstanding and visitors to the site have reported good things since its re-vamp.

The various sections are more clearly defined and easily navigable, while the design is crisper, funkier and more interactive. Indeed, the updated [ms-society.ie](http://www.ms-society.ie) is packed full of items to read and view.

The website brings with it the best bits from the older version but has added a variety of new sections. Indeed, the highly useful advice and information guide on 'Living with MS' is still there, as is the section on services and resources from MS Ireland.

If you've never been on the site before or have not visited in a while, why not check out the following:

- Download past editions of MS News
- Submit your story of living with MS to inspire and educate others
- Sign up for eNews, MS Ireland's fortnightly newsletter
- Donate online
- Check out the Regional Office section or Branch pages
- Participate in research.

Like the old site, there is an option to make the font size on the site larger if you prefer. Check out MS Ireland today at www.ms-society.ie.

Carers and caring

BRAIN AWARENESS WEEK is an international awareness campaign highlighting the work of neurological conditions and the experiences and issues of the people they represent. The Neurological Alliance of Ireland coordinates the Irish events every year. This year's Brain Awareness Week is set to take place from 9-15 March. The theme of the week is Carers and Caring, and MS Ireland is participating in the event.

Each Region is hosting an event, mainly targeting carers. Check out the calendar on the website for details.

A national seminar will take place on the evening of 10 March. The keynote speaker will be Dr Tim Lynch of the new Dublin Neurological Institute. Dr Lynch will speak about the needs of the family living with MS and the services needed to meet those needs.

NAI will be hosting a daytime event on Tuesday, 10 March in the Radisson SAS, Dublin 2. The conference is titled 'Always on my mind: caring for someone with a neurological condition'.

MS Ireland and other organisations representing people with neurological conditions are inviting people to talk about their experiences of being a carer or being cared for. A selection of responses will be displayed during the Brain Awareness Week conference on Tuesday, 10 March.

To view some suggested questions to form your comments, check out our website www.ms-society.ie or just send your thoughts and experiences to Taragh Donohoe, MS Ireland, 80 Northumberland Road, Dublin 4, taraghd@ms-society.ie.

New study on experimental drug

NEW RESEARCH into Alemtuzumab, a potential new MS drug, has found that it significantly reduces the number of attacks experienced by people with relapsing-remitting MS (RRMS). This latest study of the drug, led by researchers from the University of Cambridge, has found that it not only stops MS from advancing in those with RRMS but it can also restore lost function caused by the disease.

Published in October, the results found that Alemtuzumab reduces the number of attacks experienced by those with RRMS by 74% over and above that achieved with Interferon beta-1a, one of the most effective therapies for similar cases of MS. Most importantly, it also reduces the risk of sustained accumulation of disability by 71% compared to Interferon beta-1a.

The research showed that many people were less disabled after three years than



at the beginning of the study. Indeed, findings suggest that Alemtuzumab may allow damaged brain tissue to repair. However, as the study was a Phase 2 clinical trial, additional research will need to be conducted before the drug is considered for approval in the treatment of MS.

“Alemtuzumab is the most promising experimental drug for the treatment of MS, and we are hopeful that the Phase 3 trials will confirm that it can both stabilise and allow some recovery of what had previously been assumed to be irreversible disabilities,” says the principal investigator, Alastair Compston, Professor of Neurology at the University of Cambridge.

The Phase 2 clinical study involved 334 patients who had been diagnosed with early-stage RRMS but had not previously been treated. The patients were followed for three years. Research continues.

Positive results from long-term study of Avonex



PEOPLE WHO HAVE taken MS-treatment drug Avonex for up to 15 years experience reduced disability progression and improved quality of life, a long-term study has revealed.

The results of the ASSURANCE (ASSessment of Drug Utilisation, EaRly TreAtmeNt, and Clinical OutcomEs) study were released last autumn. It represents the long-term follow-up of patients who participated in the

original Phase 3 pivotal trial for Avonex back in the Nineties.

The follow-up looked at the long-term benefits of Avonex therapy in people with relapsing-remitting MS versus those not on it. Avonex users had been taking the drug for between three and 15 years.

Participants in the study taking Avonex reported significantly lower disability progression and a greater quality of life. They also enjoyed a significantly greater sense of independence in self care and significantly more independent living. ASSURANCE was an open-label, retrospective study, reported by patients.

“This level of impact on disability and quality of life over the course of 15 years reinforces the real-life benefits and proven clinical effectiveness of Avonex,” says Thorsten Eickenhorst, vice president of Global Medical Affairs, Biogen Idec, makers of the drug.

The most common side effects associated with Avonex are flu-like symptoms, including myalgia, fever, fatigue, headache, chills, nausea, vomiting, pain and asthenia.

Mastering MS booklets published



PHARMACEUTICAL COMPANY BAYER Schering Pharma, which manufactures the MS drug Betaferon, has released a series of booklets to help people with MS. The Mastering MS series is aimed at highlighting how MS can affect a person's personal relationships and work life. The campaign hopes to show that "with the right tools people with MS can continue to lead physically and emotionally fulfilling lives".

Some booklets to be released so far include: 'Life with MS: Mastering Your Career'; 'Life with MS: Mastering the Essentials'; and 'Life with MS: Mastering Relationships'.

'Mastering the Essentials' will act as a good guide for those who have just been diagnosed with the illness, as well as for their relatives and friends. Explaining the ins and outs of MS, it lists useful facts and endeavours to provide readers with the right resources and information.

Meanwhile, 'Mastering Relationships' looks more closely at the relationships we have with family and friends, and how these can be affected by MS. It includes some tips and advice on keeping relationships strong.

The 'Mastering Your Career' brochure is particularly interesting, and provides a step-by-step guide to dealing with your job upon diagnosis. It offers stories from people who faced dealing with both MS and their careers and who overcame certain issues.

You can order the Mastering MS series from Bayer Schering Pharma on 01 2999313 or from Multiple Sclerosis Helpline at 1850 233 233.

Tax matters

The amount of tax relief on medical expenses has been reduced. For expenses up to the end of 2008, the tax relief you get is either 20% or 41% of your expenses, whichever is the highest rate of tax you pay. This still applies for nursing home fees, but for all other medical expenses from 1 January 2009, relief is given at the rate of 20%. You can claim relief on fees charged by doctors and consultants and many of the items or treatments prescribed by them. You can claim tax relief at the end of the tax year by completing the form MED 1, which is available from your regional Revenue office. It can also be downloaded from www.revenue.ie or phone Lo-call 1890 30 67 06.

Banking on the brain



Pictured at the launch were Dr Michael Farrell, Consultant Neuropathologist at Beaumont, left, and Sports Commentator Jimmy Magee, whose son made the decision to donate his brain to research

IRELAND'S FIRST EVER Brain Bank has been launched in Dublin. The Royal College of Surgeons in Ireland and Beaumont Hospital opened the Bank in October.

The aim of the Bank is to facilitate brain donation through consent and to disseminate high quality brain tissue to neuroscience researchers in Ireland and elsewhere. Before the launch, Ireland had been the only European country not to have a national Brain Bank.

"It's obviously quite a new idea in Ireland, but so far the response has been very positive. Since the launch in October we've been getting growing interest," says Hannah Lyons, Project Co-ordinator, Dublin Brain Bank.

At the moment, the Brain Bank is concentrating on neurodegenerative disorders, and is seeking donations from people with MS among other illnesses and diseases such as Alzheimer's disease; Parkinson's, epilepsy and motor neurone disease. Healthy brains, those without the disorders, are also being sought as they allow researchers to compare normal with abnormal tissue.

To become a donor you must be over 18 years of age and give permission to have your brain tissue recovered after your death and preserved for further research. Consent can be withdrawn at any time.

For further information about the Brain Bank go to www.rcsi.ie, call the Brain Bank at 01 797 4757 or email brainbank@rcsi.ie. You can contact Ms Lyons directly at 01 809 2706, and she'll be happy to answer any queries.

Dublin Neurological Institute opens

THE DUBLIN NEUROLOGICAL Institute at the Mater Hospital has finally opened to the public, after a number of years of fundraising, development and renovations. The new centre – the first of its kind in Ireland – provides diagnosis and treatment services as well as a drop-in service for people with neurological conditions.

Those with MS are among the beneficiaries. On the first Monday of each month people with MS (both new and return patients) are seen in the out-patients clinic. In the next few months, the clinic will be operated weekly.

Opened by President Mary McAleese in September, the Institute is hoping to double the intake of those with neurological disorders to the Mater. Up until its launch, the Mater saw 3,500 people with neurological conditions each year; this figure is now increasing.

Speaking about the Institute, Professor Tim Lynch,



Professor Tim Lynch

Consultant Neurologist and Founder of The Dublin Neurological Institute, said: “The need for this institute is great. This facility will allow patients, their families or carers more support and access to information needed to face any fears or anxieties they may have regarding their condition.”

The institute has been fully renovated after The Sisters Of Mercy donated the building to the Neurology department of The Mater Hospital. “The new building has greatly improved our infrastructure,” says Prof Lynch. “We have more room and facilities to

see patients and provide more and better information on a wide range of issues affecting people with neurological conditions.” There is currently an impressive list of services in operation.

The Institute is a not-for profit trust and relies on the kind donations from organisations and individuals. If you would like to donate to the Institute or volunteer, go to www.neurologicalinstitute.ie or call 01 830 3482.

Beautiful building for new Neurological Institute

Finola Kelly talks about her experience with the new Dublin Neurological Institute

ON THURSDAY, 5 February I went for my nine o'clock appointment in the new Neurological Institute. It was a wet and miserable morning and I felt the same as I went into yet another location to have my half-yearly check. I should point out here that in the past locations of clinics have been movable feasts.

Instead, I found the new location to be quite staggeringly beautiful. I thought I had died and gone to heaven, or had gone to the Mater Private by mistake!

I entered the waiting room and spied sofas and comfortable-looking lounging chairs. It was like entering a private salon, in a beautifully restored Georgian house, with such a relaxing ambience. In the corner of this beautiful room came the sound of music. Not your blaring, nauseating pipe music, but the soft tones of a baby grand piano.

By this stage I was still convinced I was in the wrong place. I whispered to the man beside me, “Is this the MS Clinic?” He nodded in confirmation. “Lovely, isn't it,” he said.

We all know that the health service has been greatly neglected by successive governments over the years. Was there light at the end of the tunnel? I reserve my judgement; a clog does not become a glass slipper and only time will tell.

I left the clinic by going to the back of the house where there is a lift (yes, an actual lift) to street level. I was gobsmacked – a baby grand, soothing music and a lift.

A brilliant hat-trick for patient care and comfort. I left the premises of Ireland's first Neurological Institute feeling that perhaps 'Centres of Excellence' could have a future, unless of course the present downturn in the economy cuts off finances for these centres in half flow.

Ten ways to clear your credit-card debt

Pay off those credit-card bills with timely advice from **Bob Quinn QFA**



Bob Quinn

THE AVERAGE PERSON spends about €1,374 over Christmas, according to research compiled by consultants Deloitte recently. Some €688 is spent on gifts, €422 on food and the remaining €264 on socialising.

There was an informal poll taken on www.itsyourmoney.ie just before Christmas, which showed that 33% of people had intended paying for Christmas with their credit cards. So now that your bills are flowing in at an almighty speed, what decisive action can you take to reducing your exposure to unmerciful credit-card companies?

HERE ARE A FEW PRACTICAL AND EASY-TO-IMPLEMENT TIPS:

1 Switch your credit-card balance to a more competitive rate. The AIB Click card is the most competitive right now at 8.5% APR. While this rate is not one of those pesky introductory offers, there are nevertheless 73 terms and conditions attached to the card. As always 'caveat emptor' – buyer beware.

2 Bring your lunch to work. It costs about €2 to make a sandwich whereas it costs on average €6 to buy it in the local deli. Butter your own bread and you'll save over €900 in 2009.

3 Buy generic food brands. It's time to discard the snobbery and try own brands. Many are of comparable quality, albeit packaged a little differently.

There are big savings on tea, coffee and cereal in particular. When shopping, always compare unit price as opposed to pack price. If you can save 10 cent on a nappy and you change it six to eight times per day, that's a savings of almost €300 in 2009.

4 Shop less or online. Over half of all grocery shoppers shop three to four times per week, according to research conducted by the Marketing Science Institute. Shoppers making a 'quick trip' to the supermarket end up buying on impulse. If impulse buying translates to €10 each time you shop, that's an extra €2,080 per year. Shop once per week and it's €520 on impulse purchases versus €2,080 per year. That is a realistic savings of €1,560 per year.

5 Rethink your broadband/tv/phone providers. There are many good offers out there and the telecoms industry is so competitive that there's always a good deal to pick up. The status quo is not your friend here. Consider downgrading your package if you are not making the most of it. Sky's basic package will cost you €246 per year, as opposed to their advanced package of €852 per year, saving you €606 in 2009. Check out ComReg's site, www.callcosts.ie, where they compare a number of options.

6 Buy a more economical car. Save yourself almost €900 by driving a more economical car. If you drive 18,000 miles per year and your car averages 25 miles per gallon, it will cost €3,096 (assuming 95 cent per gallon). A car that averages 35 miles per gallon costs just €2,211. The saving pays for your road tax and insurance in 2009! Or you could always take the bus ...

7 Watch those bank charges. Going overdrawn on an unauthorised overdraft every month will cost €5.15 per item with AIB. To set up an authorised overdraft with AIB will cost €25.39 initially, with this charge recurring every year. Switch your current account to Halifax and benefit from zero overdraft set-up fees. For those of you with money in your current account regularly, make sure

Competition!

THE MONEY DOCTOR HAS TEAMED UP WITH **MSNEWS** TO GIVE THREE LUCKY READERS A TOTAL FINANCIAL MAKEOVER THROUGH A MONEY DOCTOR PERSONAL FINANCIAL REVIEW WORTH €350.

The Review is a totally independent and unbiased view of your finances and takes in excess of an hour. Financial advisers go through all your finances with you and we write a personalised

plan of action based on your needs.

Some of the typical areas covered by the review are life assurance, debt management, investment advice, loan advice, pension advice, wills and estate planning.

To enter, simply reply with your name, address and contact number to competition@moneydoctor.ie or write to Competition, The Money Doctor, Providence House, Lower Kilmacud Road, Stillorgan, Co Dublin before 28 February 2009.

Anyone can avail of a Money Doctor Personal Financial Review regardless of

their circumstances. For more information, please email bquinn@moneydoctor.ie or call Bob direct on 087 952 7060.

As part of the close association between The Money Doctor and MS Ireland, any fees charged by The Money Doctor will result in a donation of 10% back to the Society. MS Ireland will not be furnished with names or details of those availing of services. However, the competition winners' names and addresses will be passed on to MS Ireland for their website and MSnews.

you're getting paid interest on it. Call your bank now. It usually involves simply filling out a very straightforward form.

8 Pay off high-interest debts before your mortgage. If you are being smothered by credit-card bills, personal loans and a hefty mortgage, consider switching the mortgage to interest-only for a period in order to get on top of the bills that cut off the air supply to your disposable income. It should be carefully considered; consult your Money Doctor Adviser for more information.

9 Set up a loose change jar. When you come home empty your pockets of your loose change. You will be very surprised how quickly a few quid accumulates.

10 Contact your Money Doctor Adviser to set up an 'Inner Circle'. The Money Doctor Inner Circle is a financial coaching session for small groups of friends or colleagues with similar needs. For instance, you may want to discuss options with regards to life assurance or mortgage protection policies.

Congratulations. If you followed the above steps, you have just saved yourself over €4,000 in 2009 and regained your financial independence!

BOB QUINN QFA is a Money Doctor Adviser at The Money Doctor. Bob is a member of The Institute of Bankers and a Qualified Financial Adviser. Check out *The Money Doctor Finance Annual 2009* in all good bookshops.

Contact Providence House, Lower Kilmacud Road, Stillorgan on 01 278 5555 or Bob directly on bquinn@moneydoctor.ie or 087 952 7060.

Research sources show MS resources in Ireland are inadequate

TWO DATA SOURCES that aim to compare and contrast various different aspects of MS treatment in Europe and worldwide have been launched.

The 'Atlas of MS' is an interactive database exploring international data on a range of areas associated with MS, including prevalence, diagnosis, services, resources and quality of life implications. It has been developed by the MS International Federation and the World Health Organisation.

In the category 'Number of neurologists per 100,000 of the population' Ireland ranks 40th out of 40 in Europe and 68th out of 100 in the world.

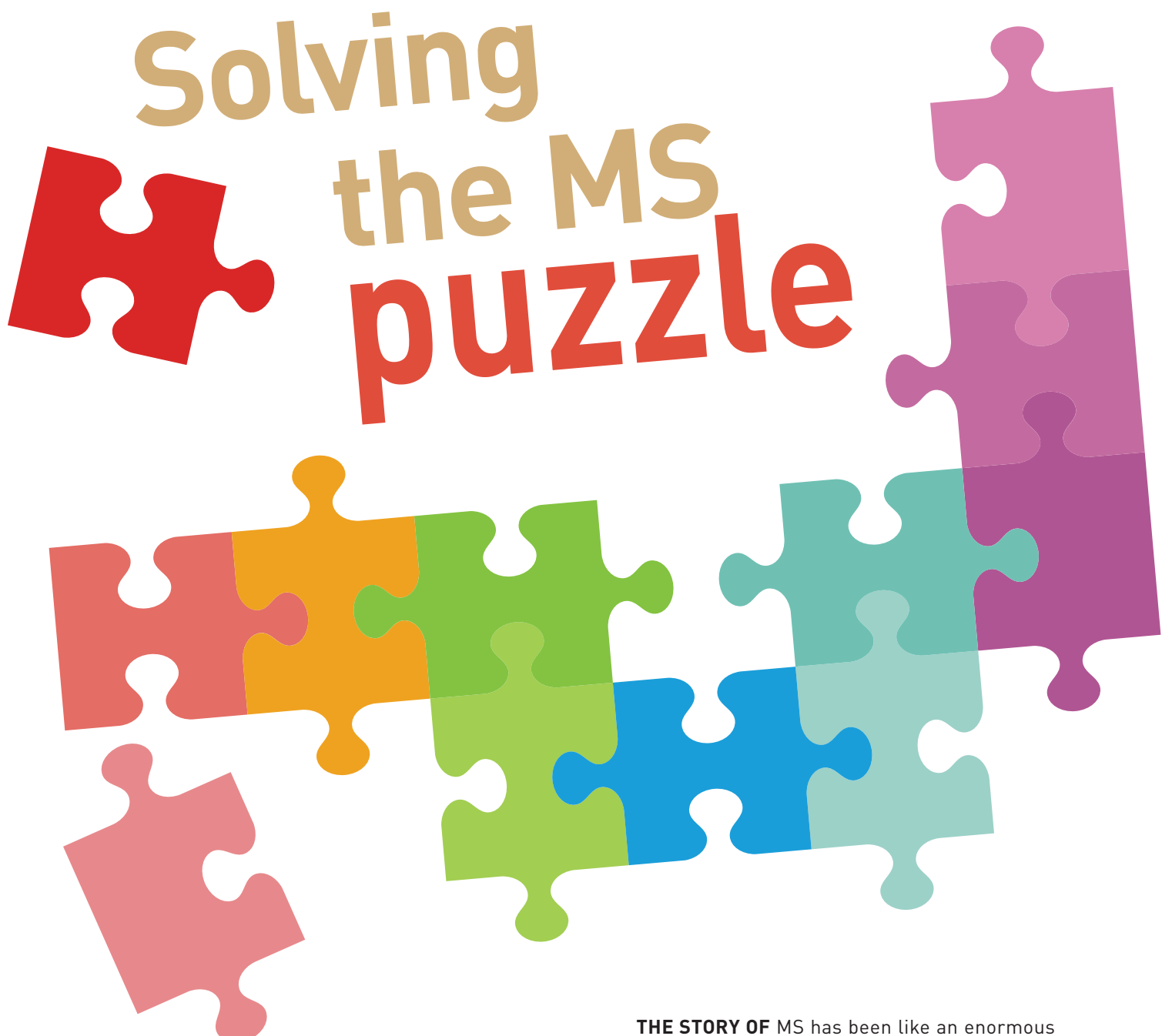
Allen O'Connor, Chairman of MS Ireland and person with MS, says, "This is a sad reflection on our existing services which are excellent and led by dedicated neurologists, MS nurses and health professionals."

The European Multiple Sclerosis Platform also launched its 'MS Barometer', which charts the situation faced by people with MS across Europe in seven key areas including access to treatment and employment. Out of a possible 270 points Ireland scored 130, similar to Latvia, Croatia, Spain and Hungary. Top of the list was Germany with 240 points and Denmark with 237.

MS Ireland has long campaigned for mass investment in Irish neurology services and again calls on the Government to publish and implement the Review of Neurology and Clinical Neurophysiology Services in Ireland, which was completed 18 months ago.

Check out our website for more information on each of these data sources – www.ms-society.ie.

Solving the MS puzzle



MS research is the cornerstone of understanding MS, which will lead to better treatments, interventions and hopefully, one day, a cure. While medical research is the mainstay, quality of life research is now becoming a significant theme as it is seen to make an immediate impact on the person with MS. This article looks at the development of medical research and explores MS Ireland's research agenda.

THE STORY OF MS has been like an enormous jigsaw puzzle, with researchers around the world coming together to find different pieces. Of course, like any jigsaw some pieces have been more difficult to find than others, but gradually those pieces are coming together, and a fuller picture is being developed.

Dr Dhia Chandraratna, International Scientific and Medical Research Officer with the Multiple Sclerosis International Federation (MSIF), says all MS research is important for lots of reasons.

"It is estimated that about two million people around the world have MS. That doesn't sound like a high number but when you look at the social impact it's huge. The cost of MS is enormous, and we still don't know the cause of the disease. Therefore,

continued MS research is essential.”

The story of MS goes back centuries but it was Frenchman Jean-Martin Charcot (1825–1893) who became known as the father of neurology and first found the characteristic scars of MS.

In the 20th century a number of individuals added contributions to the study of MS, including Ian McDonald, Larry Jacobs and Douglas McAlpine, and our own Geoffrey Dean, who was awarded an honorary doctorate by UCD last year for his contribution to MS research. Prof Hans Lassman is also recognised as a pioneer in the fields of neuroimmunology, researching the immune surveillance of the nervous systems and mechanisms of demyelination. Each have helped add to the story of MS, and have helped paint a picture of MS today.

The use of MRI scans had a huge impact on the area of MS research, allowing researchers to track the disease in individuals. It confirmed that MS is often very active even when a person displays no symptoms.

The first successful scientific clinical trial of a treatment for MS took place in 1969, when a group of people who were having acute attacks of MS were given the steroid ACTH. Steroids are now a common treatment to ‘dampen’ the inflammation occurring during a relapse.

While some clinical trials did take place during the Seventies, it was in the Eighties that an explosion occurred. New discoveries were made, including the white blood cell type that can cause the damage to myelin in MS – the macrophage – and the first drug treating MS. During the Nineties a study of some 15,000 people with MS took place and for the first time it was clearly shown that there is a genetic determinant to acquiring MS.

However, one of the biggest success stories of the Nineties was the introduction of disease modifying drugs. The discovery of beta interferon 1b, beta interferon 1a and glatiramer acetate revolutionised the treatment of MS. These proteins form the basis of the four main disease modifying drugs: Betaferon, Avonex, Rebif and Copaxone.

In 2004, after much research, a fifth disease modifying drug, Tysabri, was introduced. Although it was taken off the market for a period due to safety concerns it is now a licensed drug for the treatment of relapsing-remitting MS.

In 2007, scientists identified two genes that may raise the risk of MS. In a large-scale study, international researchers scanned the entire human genome of over 12,000

‘People with MS and the neurologists treating them are acutely aware that there is still no cure for MS’

people for MS risk factors.

According to a report by MSIF, a total of €77m was spent by national societies on all forms of MS research in 2007, 56% of which was spent by the US MS Society and 11% by the Canadian society. The overall investment in research is much greater as the €77m does not include research performed by pharmaceuticals, universities or other private organisations.

Dr Chandraratna believes that the investment is proving worthwhile. “We have a much better understanding of the genetic and the environmental risks of MS, and have made inroads in terms of diagnosis.

“There has been lots of research into the repair and progression of the disease but it’s still important that we understand what’s causing it, so we can eventually find a cure; the two must run concurrently.”

Dr Una FitzGerald, a researcher at National University Ireland, Galway, echoes these sentiments: “People with MS and the neurologists treating them are acutely aware that there is still no cure for MS. Most therapies target the early relapsing-remitting phase of the disease. Symptomatic relief may be given to patients during the later chronic, degenerative phase, but researchers agree that these treatments generally do nothing to address the underlying biological signals.”

The challenges facing MS researchers remain considerable, according to Dr FitzGerald. For example, we still don’t know what triggers the switch from the relapsing-remitting phase of MS to the chronic degenerative phase.

“The notion that a cure for MS is possible would depend on a convergence of evidence from the scientific community, demonstrating a single trigger or causative agent in MS. The bulk of the scientific literature suggests that this isn’t the case. In other words, MS arises in different people, for different reasons,” says Dr FitzGerald. However, both Dr FitzGerald and Dr Chandraratna are optimistic that a cure will be found.

‘We have a much better understanding of the genetic and the environmental risks of MS, and have made inroads in terms of diagnosis’



A timeline of MS Research

- | | |
|--------------------|--|
| 1421 | First documented case of MS: St Lidwina of Schiedam |
| 1868 | First correlation of MS clinical symptoms with central nervous system. The disease is named ‘Sclerose en plaques’ by Jean Martin Charcot |
| 1869 | First attempts to treat MS with gold chloride, zinc, sulphate, silver nitrate, strychnine and electrical stimulation (by Charcot) |
| 1943 | First detailed description of the composition of myelin |
| 1963 | First understanding of familial susceptibility to MS |
| 1969 | Completion of first controlled clinical trial |
| 1982 | First use of MRI to image lesions in living patients |
| 1983 | First report of temporary control of chronic-progressive MS with the immunosuppressive drug Cytoxan (widely disputed throughout decade) |
| 1984 | First modern documentation of cognitive problems in MS |
| 1988 | First demonstration, using MRI, that there is significant lesion activity in MS brain, even when there are no symptoms |
| 1980s–1990s | Numerous clinical trials get under way |
| 1993–2002 | Discovery of the beta-interferons and glatiramer acetate which from the four common MS drugs, Copaxone, Rebif, Betaferon and Avonex |
| 2003 | First stem cell studies into MS carried out in Italy |
| 2004 | Introduction of Tysabri (it is withdrawn in 2004 but later re-introduced in 2006) |
| 2007 | Two genes associated with cause of MS found |

Source: 1462–1990s – National Multiple Sclerosis Society, USA

Current research

THERE ARE THOUSANDS of MS research projects underway all around the world, so it would be impossible to give an overview of all of them. However, below you will find some information on treatments and developments that MS Ireland members have asked us about over the past year.

MS VACCINE

In MS the body's immune system attacks itself, causing inflammation. Researchers are exploring the possibility of using a vaccine to stop the body from doing this. Prof David Wraith and his team in the Experimental Pathology Department at the University of Bristol have successfully tested the vaccine on animal models. This year, the vaccine is due to be tested on 60 people with MS. Dr Wraith hopes that the research will be completed by 2012.

FINGOLIMOD

This is an oral tablet that works by binding to the surface of immune cells, trapping them in the lymph nodes and preventing them from attacking cells in the central nervous system. There is also some evidence to suggest it has a neuroprotective effect in the brain, which could be helpful in preventing or slowing down disability.

The manufacturers, Novartis Pharmaceuticals, hope to submit the drug for licensing by the end of 2009.

LOW DOSE NALTRAXONE (LDN)

LDN is a licensed drug used in treating AIDS. As MS, like AIDS, is an auto-immune disease, some suggest LDN may have some benefits for people with MS. Anecdotal evidence suggests that MRI lesions halt and some symptoms may be relived. However, there is no clinical evidence to prove LDN's efficacy.

An Italian study will begin trials on LDN in 2009.

ALEMTUZUMAB (PREVIOUSLY KNOWN AS CAMPATH)

A 2008 study showed that after three years 77% of low-dose Alemtuzumab and 84% of high-dose alemtuzumab receivers had experienced no relapses, compared with 52% of people receiving beta interferon 1a. The results also show that Alemtuzumab reduced the risk of sustained disability by 71%. It is now entering phase III trials. The final report is due in 2011.



CLADRIBINE

Cladribine is currently licensed to treat certain forms of leukaemia and appears to interfere with the behaviour and proliferation of cells of the immune system. It can be taken by injection but an oral version is proving more effective in trials. Results released from the two-year CLARITY study in January 2009 showed that Cladribine reduced relapses by 58% among the 1,326 people who took Cladribine tablets for 8–20 days during each year of the trial. Further studies will continue in 2009.

VITAMIN D

Previous studies with vitamin D have shown that Northern Europeans have an increased MS risk if they live in areas receiving less sunshine. This supports a direct link between deficiency in vitamin D, produced in the body through the action of sunlight, and increased risk of developing the condition. A number of trials are currently taking place, including one in St Vincents Hospital, Dublin.

STEM CELLS

On 30 January, The Lancet Neurology published the results of a Chicago trial involving stem cell transplantation in people with relapsing-remitting MS. The results of the study of around 20 people show that the treatment stopped progression of disability and could potentially reverse the damage caused by MS. Further research with larger numbers of people is underway.

To keep up to date with developments in research check out the research section on our website. The MSIF produces a weekly newsletter, 'Making Connections', outlining research developments. Sign up on its website: www.msif.org.

MS Ireland and research

MS IRELAND HAS a long tradition of supporting national and international research. Although modest by international comparisons, its investment represents a commitment by the Society to support, promote and prioritise research.

Since 1982 MS Ireland has invested over €1.2m in MS research. A number of key projects were funded exclusively or jointly by MS Ireland in that period. Much of the research focused on the pathogenesis of MS. (Pathogenesis refers to activities such as epidemiology, genetics, infection and DNA.) Funds have also been used to support international research. In 2003, for example, MS Ireland donated €30,000 to the Sylvie Lawrie Centre, a US MS research centre.

In 2007 MS Ireland implemented a strategic planning consultation process. Contributions were sought from members, the public, staff, sister organisations and others on the work and priorities of the Society. Research was identified as one of five priority areas for MS Ireland.

'Making It Happen' is MS Ireland's strategic plan until the end of 2011. In that plan the Society is allocating a minimum of €100,000 per annum to support and promote research. This, coupled with a commitment to improve information, collaboration and research funding, lays out clear guidelines for the research function of MS Ireland.

The communication of information relating to MS is vitally important to keep people affected by MS up to date with developments. The research section of the website has been revamped to make it more interactive and informative. The news

section contains updates on all research news and the 'participate in research' section gives information on the type of research people with MS can get involved in.

RESEARCH PROGRAMME 2008

MS Ireland's Medical Advisory and Research Committee advertised for submissions in early 2008. Seven suitable applications were sent for peer review. From these, MS Ireland allocated funding to two projects. An overview of each is on the next page.

MS Ireland has also supported a number of scientific conferences in Ireland and has provided some funding and support to St Vincent's Hospital for their research into epidemiology, vitamin D and quality of life.

Its biggest research project in 2008 is the ongoing 'Getting the Balance Right' programme. The nationwide exercise, activity and health promotion research programme for people with MS has enlisted over

1,000 people on the research part of the programme. The aim of the research is to assess the impact various physical interventions may have on people with MS. The interim results look positive, and the final report is due to be published at the end of the year.

RESEARCH PROGRAMME 2009

MS Ireland has just announced a call for applications for this year's fund.

Three themes will be adopted:

- Basic and clinical science: Mechanisms of nerve damage, repair and protection
- Quality of life
- Service delivery.

MS Ireland hopes to work collaboratively with the Health Research Board, the Medical Research Charities Group and the MS Society in Northern Ireland. The application, selection and review process will take a few months but we will update you with progress.

MS Ireland's 'Solving the MS Puzzle'

MS Ireland is committed to supporting research but we need your help to do so. We need to raise €100,000 and more each year. We are asking all our friends and supporters to join our 'Solving the MS Puzzle' campaign and donate money to the fund. Research is the best way to find better treatments and interventions and will hopefully lead us to a cure for MS. MS may be big puzzle, but we can all be part of the solution, one jigsaw piece at a time. Please support us today!

You can download your jigsaw piece at www.ms-society.ie or send your donation to MS Ireland Research Fund, MS Ireland, 80 Northumberland Road, Dublin 4.



Solving the MS puzzle



We can all be part of the solution.
One jigsaw piece at a time.

Promising projects



There are two projects currently funded by MS Ireland.

PROJECT 1: In-vitro assessment of the efficacy of the nootropic nefiracetam to enhance plasticity after experimental demyelination.

Dr Mark Pickering of the Conway Institute, University College Dublin

Difficulties with memory and cognition are problems experienced by many people with MS, and there is no specific treatment available for this effect of the condition at present. It is most likely that these problems occur when the loss of myelin affects a part of the brain known as the hippocampus.

In this project, a tissue culture model of the hippocampus will be treated to cause a loss of myelin, and the effect this has on the plasticity will be measured. Tissue will also then be treated with nefiracetam, a drug previously shown to protect memory, to investigate if this alleviates the effects of demyelination. If any benefits are shown in tissue culture with this drug, it may open the door for clinical investigation of this drug for people with MS.

PROJECT 2: Endoplasmic Reticulum as a component of neurodegeneration in MS grey matter lesions.

Dr Una FitzGerald, National Centre for Biomedical Engineering Science at the National University of Ireland, Galway

In a joint collaboration with Professor Stephen McQuaid of Queen's University, Belfast, Dr FitzGerald will examine the pathology of lesions occurring in the grey matter of MS patients, i.e. lesions in the outermost layers of the brain. This area of the brain is increasingly under the spotlight as it is known that lesions develop all over the grey matter and these may be responsible for chronic neurodegeneration occurring in the later stages of MS.

Many researchers believe that factors that trigger pathology in the grey matter are different to those that cause damage elsewhere.

To examine this, post-mortem material will be obtained from the UK MS tissue bank and the archives of the Belfast Bank. Tissue sections will be stained with appropriate antibodies and the pattern of staining analysed. This work will add to the body of knowledge surrounding how grey matter lesions are generated.

Irish research in action

UNA FITZGERALD has been a recipient of MS Ireland research funding. In 2005, Dr FitzGerald received 'seed' money from MS Ireland that helped to fund a -80 degree freezer. This is a secure freezer that the labs in Galway use to store precious MS tissue samples. Its presence has been crucial to the setting up of tissue studies there. This year she was awarded €15,000, which will allow expansion of the Endoplasmic Reticulum (ER) stress-related work, which follows on from a past collaboration with Dr Stephen McQuaid of Queen's University Belfast.

Dr FitzGerald got involved in MS research when she was working as a postdoctoral researcher in the laboratory of Professor Sue Barnet at the University of Glasgow.

"I was fortunate to spend over four years working on a brain cell called the oligodendrocyte. The oligodendrocyte produces myelin, the fatty substance that insulates nerves, accelerating the speed of nerve impulse conduction tenfold. It is this cell which fails or is under attack during MS.

"Having learned how oligodendrocyte life and death can be controlled in the lab, I developed a strong desire to understand how oligodendrocytes behave in the brain of MS patients. It was for this reason that I initiated the study of ER stress signalling in post-mortem brain samples."

For all researchers, Dr FitzGerald says financial support from organisations like MS Ireland is essential.

"Although Science Foundation Ireland and the Health Research Board have been providing significant levels of funding to researchers all over Ireland, competition for this money is fierce. The current economic climate is making many researchers very nervous and apprehensive about future sources of funding. Continuing support from charities such as MS Ireland may be the safety net that helps to maintain smaller research groups who have limited funding opportunities.

"Data from this research can be used as the basis for future grant applications, further emphasising the long-term impact of the financial support provided by MS Ireland," she says.

21 YEARS ON THE ROAD



MS Ireland is delighted and honoured to be celebrating 21 fantastic years of charity trekking trips. Since 1989 we have organised some 46 charity walks, bringing over 2,500 people to over 15 beautiful destinations around the globe. To celebrate our 21st birthday we talk to some of the people who have made the walks so successful over the years.



THIS YEAR, AN idea – first formed in the mind of Lorna Mitchel – celebrates a very special birthday. The MS Walks officially turns 21. Through the last three decades we have been organising charity treks all over the world. Spain, Peru, Tanzania, America and Nepal are just the highlights of a long list of destinations we have made our mark on, and we have no plans of slowing down!

For us, the MS Walks personify what is good in people in many ways. Most importantly, they bring in huge revenue for the MS Society, helping to provide services for people with MS in Ireland. MS Walks has become one of the most successful charity events in Ireland. Each year some 160 to 170 people get involved.

It boils down to the one story, the one smile, the one week of respite, the one moment you realise your diagnosis will not stop you and the one friend, sister or stranger who takes on these challenges to help someone else. It truly is altruism at its best.

There is such a huge network of walkers now affiliated with MS Walks that we truly are like one big community. Some of these walkers have been trekking the globe for MS Ireland for nearly 20 years, some individually raising up to €100,000. Many have forged long-lasting friendships, but at the same time the new people who come forward each year are welcomed in with open arms.

There's a real sense of achievement that comes with completing a walk. Some marvellous memories have been created. Particularly poignant is when people with MS partake in the walks and complete them – everyone feels a swelling of pride on their behalf. One very special lady who has MS herself came on a trek last year. She worked really hard on her fitness but was still worried about it. You can imagine her joy when she happily led the walk on the last day having done every step of the way – a special moment.

We must also say a very big thanks to our walk leaders, doctors, physiotherapists, cooks and all who helped out over the years and whose support made these walks possible.

Most of all we would like to say a very special thanks to all of those who have walked with us over the years; we truly appreciate the amount of effort you have put in. The success of these walks in down to you all – to your enthusiasm, energy and your absolute passion for the walks and for MS Ireland. We hope that you will continue to join us as we trek in aid of this very worthwhile cause.

Cathryn O'Leary has taken over the mantle from Lorna Mitchel, and now co-ordinates all the walks for MS Ireland. She is ably assisted by Natasha Duffy.



Magical memories

Lorna Mitchel, the founder of MS Walks, talks about her experiences over the past 21 years

I have been privileged to have been on many walks in many countries over the past two decades, but the first that really stood out for me was the Camino de Santiago. We had come up with the idea to do the walks in 1988, and came across a book called 'Pilgrims' Footsteps' by Bert Slader, which recounted his solo walk along the Pilgrim Road to Santiago. It turned out Bert lived in Northern Ireland and we visited him. We formed a long-lasting relationship and for many years he led the walk on the Camino.

Since that very first year we've never looked back and along the way have created some wonderful stories and memories.

On one occasion, we were asked to sing in front of nuns in a convent, who all sat behind a grille. We had practised our song and thought we were great, but when we started to sing we were on completely different notes. It was an absolute disaster but behind the grille sat all of these nuns with hands up to their mouths in absolute stitches!

On another occasion, in a village called Ledigos in Spain, sadly now deserted, someone got a guitar and everyone started singing. Slowly, we could see these faces coming out from little doors around the village, and they came and joined us. They sang Spanish songs and we sang ours. We danced in the street; it was a wonderful memory.

Camino hasn't been the only location for the walkers, of course. Our first walk was in France, our second in China. Other locations have included Goa in India, Thailand, Tanzania and Nepal.

Without a doubt the walks have been very, very special to me, but I realised there was a time to pass on the helm, and I've passed it on to a very nice and able person – Cathryn.

It's the culture, it's the architecture that brings you back, but most of all for me it was the people who brought me back. There has been just an incredible bunch of people who raised a whole lot of money over the years.



Life-changing experience

I FIRST WALKED with the MS Society in 1996 along the Camino de Santiago. I heard a radio ad inviting people to join the walk and I thought why not? My decision to join the walk was a life-changing experience.

The walk was tough but hugely enjoyable. It started in the Pyrenees and took us through some spectacular landscapes, including the Rioja district, the Cantabrian Mountains, the vast plains of the Meseta to the beautiful small farms of Galicia. We walked through beautiful small villages and towns where time appeared to stand still.

It would be hard to describe my feelings when we reached the square in Santiago after over 10 days' walk. The sight of the magnificent cathedral took my breath away.

I have just completed my 25th walk with the society and I feel honoured and privileged to have been given the opportunity to participate in them.

John O'Halloran



The right attitude

WHEN I WAS first diagnosed with MS 11 years ago, it was a shock to the system, but I have always remained optimistic and active. I love to walk and have never been one to sit around pools on holidays, preferring to venture into the towns to explore. Then one Sunday, five years ago, fate intervened. As I went to gather up newspapers, an advertisement for MS Walks caught my eye. That was it; I decided I'd give it a go.

My location of choice was the Camino de Santiago, an amazing place. I actually surprised myself that first year when I completed the walk. I did find it tough, and there were some days I swore I'd never do it again. But the Camino, the atmosphere and the camaraderie just get to you. I was hooked.

I've now walked with MS Ireland for five years, and last year I didn't find it any problem at all. In fact, it felt like the walk had been made shorter! It's about having the right attitude. The sense of achievement is palpable while the sense of pride that comes with fundraising and helping others is great.

There's a great camaraderie on the walks, and we all try to help each other during the day. I've lost the sight in one eye, and that inhibits me a bit, but people are always on hand to help. It's a place where friendships are formed.

So, I say roll on MS Walks 2009 – I'll definitely be doing the Camino again!

Kathleen Fitzsimons

There were many walkers' stories to choose from and due to space we could only print edited versions of some of them. To read full transcripts of these or to read about the experiences of other walkers, log onto www.ms-society.ie.

A VERY SPECIAL FRIENDSHIP

I STARTED WALKING for the MS Society back in 1994. There is just one short story I would like to share with you from one of my experiences in Peru which has brought great joy into my life. One day I sat in a small square in the village of Maras with a co-walker, Florence. As we watched the women knitting, and the children playing, we decided to start knitting. To make a long story short, I bought the jumper I was helping with from the lady. She was overjoyed and threw her arms around me and gave me a big hug. Her name was Sulio.

The following year I returned and brought the picture of Sulio. We found her house and when she opened the door she recognised me immediately and we exchanged

gifts. After that I kept in touch with them and in 2004 I had returned with the MS group when Sulio's husband, Miguel, ran up to me to ask me to be godmother to his daughter Flora Nora. I agreed.

In 2006, I arranged to go to them with my sister, sister-in-law and friends, where we had a very special celebration. We were introduced to all the family: grandparents, aunts, uncles, cousins, school principal, and police force. Flora Nora's grandmother cried with joy as she said this would give her granddaughter opportunities in life that she herself never had. I feel now I have a genuine commitment and a real connection in Peru; I will have to keep the visits going. It has brought me great joy.

Ellie Keating

Eye-opener



I HAD ALWAYS heard about these treks that charity organisations run to far-flung corners of the world and out of all of them the Peru trek really appealed to me. Then, about one year ago, a good friend of mine was diagnosed with MS and this gave me some kind of meaning and inspiration for the trek. I think everybody knows someone who has been touched by this disease and obviously the money raised goes to the people who need it most, which is great.

The trip was so well organised by the staff of the MS Society and every one of the trekkers were so nice and instantly made you feel welcome. 2008 was my first trek but definitely will not be my last.

When it came to the trekking, nothing I could say in words could describe the natural and man-made beauty this country offers up. The days of trekking flowed into nights of fun and camaraderie in the old towns like Cuzco and Ollantaytambo.

The obvious pinnacle of the trip was the walk to Machu Picchu. Looking through the Sun Gate to gaze upon one of the wonders of the world really is an awesome sight to behold.

This trip opened my eyes to South America, the land, the people. I will definitely undertake another.

David Whelan



Celebrate with us!

If you are looking for a challenge this year why not celebrate our 21st birthday by coming to the Camino, Peru, Nepal or Cuba. An insert on all the walks is included in the magazine or can be downloaded at www.ms-society.ie.

- CAMINO 4-16 JUNE
- PERU 4-16 SEPTEMBER
- NEPAL 31 OCTOBER-14 NOVEMBER
- CUBA 27 NOVEMBER-8 DECEMBER

For more information on the Walks, contact Cathryn or Natasha on 1850 650 950 or email fundraising@ms-society.ie.



Great craic

IN JANUARY 1999 my sister-in law Mary rang me and said she had put my name down for a walk in South Africa. I was not a walker – the furthest I walked was to the bus stop. My first long walk was in Howth and by the time I got to the top of Howth Head I thought I was getting a brain tumour. By the time I left South Africa I was hooked. In November this year I completed my 13th walk in the Annapurnas in Nepal.

Has it changed my life? Yes, in a lot of ways. I have walked in some of the most beautiful countries and continents in the world, from Northern Spain to Africa and South America and Asia. Each country has special memories for me; the local people we meet, the guides, the places we see and the experience we get out of each walk.

The experience I enjoy the most is walking along with my fellow walkers from every part of Ireland and getting to know people, listening to all the different stories and learning so much about life and people, or just taking time out to clear the head. At night it is great to sit around and unwind with a glass or two of wine, a chat, craic and a sing song.

Arriving home can be happy and sad, saying goodbye but knowing the reunion or Christmas party is just a short time away.

Betty Tuite

European traineeships launched



THE EUROPEAN COMMISSION has launched a traineeship for people with disabilities. The commission is offering university graduates with disabilities the opportunity to work and live in Brussels for five months.

It is hoped the traineeships will help facilitate people's professional integration and increase opportunities for future employment.

The scheme will also allow trainees to become familiar with the workings of the European institutions. In addition, it will provide the Commission with 'the contribution and positive experience' that those with disabilities bring.

The pilot session began in November 2008 and is set to continue up until 31 March, with dates for new applications to be announced shortly.

Trainees will be assigned to various units or services within the European Commission, depending on their educational and university background.

The work will be similar to that of an administrator, such as participating in meetings at different levels, document handling, word processing and filing. Trainees will also assist with high-level administrative and logistical tasks such as organising working groups, public hearings, preparing reports and answering queries. Translator traineeships are also available.

The traineeships are open to all nationals of EU member states with a documented disability. Participants must have at least a bachelor's degree and good knowledge of two of the EU's official languages, one of which must be English, French or German.

In 2008, trainees received a contribution of just over €1000 per month worked. However, there is possibility to have travel expenses reimbursed, and those with disabilities may also receive a supplement.

To access the application form for the traineeships go to ec.europa.eu/stages/information/stage_handicapes/Description_programme_EN.pdf.

Scholarships available for third-level students with MS

PEOPLE WITH MS either entering or currently in third-level education have the opportunity to receive a scholarship from Bank of Ireland's Millennium Scholars Trust. The Trust awards scholarships to people with talent and ability, who, because of economic circumstances or barriers such as disability, are prevented from reaching their full educational potential.

Bank of Ireland is awarding up to 60 scholarships each year up until 2010. For those entering or currently in third-level the closing date is 2 March 2009. For those seeking the scholarship for creative/performing arts, the deadline is 1 April 2009.

To be eligible, candidates must be proposed by a nominating body, one of which is MS Ireland. The Trust is administered by National College of Ireland (NCI), on behalf of Bank of Ireland.

For further details lo-call 1850 221 721 or go to www.ncirl.ie or www.boi.com/millenniumscolars.

FACTSHEETS ON DISABILITY LAUNCHED

The Citizens Information Board (CIB) has launched a number of factsheets on disability that summarise the various cash payments, benefits and other services available for people with disabilities and their carers.

They comprise:

1. Disability payments
2. Health services for people with disabilities
3. Supports and entitlements for carers
4. Education, training and employment
5. Housing for people with disabilities
6. Transport and travel for people with disabilities
7. Income tax for people with disabilities.

The factsheets are available in alternative formats such as large print, which will be good for many people with MS.

Contact your regional CIB at:

- Dublin North and North East Region: 01 824 5200
- Dublin West and Midlands Region: 01 462 0444
- Dublin South and South Eastern Region: 056 776 5176
- Southern and Mid-Western Region: 021 422 2280
- West and North West Region: 091 560 370

A cause for celebration



The 2008 National Conference was a great success, combining information with entertainment, not to mention the gala dinner and awards ceremony



WITH A THEME of rehabilitation, the overall feel of 2008's MS Ireland National Conference was one of hope in the face of adversity. The event, which took place in Galway in October, was a well-balanced mix of education, information and enjoyment.

The conference weekend started with a health professional's day attended by more than 125 physiotherapists, occupational therapists, speech and language therapists, public health nurses and other health care professionals. As with the National Conference the focus of the day was neurorehabilitation.

Six presentations were given throughout the day. Dr Belinda Weller, Consultant Neurologist in the Western General Hospital, Edinburgh, spoke about 'The rehabilitation approach'; Dr Susan Coote, Physiotherapy Department, University of Limerick discussed the pilot study results of Getting the Balance Right; Jill Harding-Clarke, Neuropsychologist, Rehab Care, Galway spoke about 'Cognitive dysfunction'; Susan Prenter, Allied Health Care Professionals Manager, Western Trust, Northern Ireland spoke about 'Meeting the demands of the multidisciplinary team'; Sancha Mc Court, Education Coordinator, National Rehabilitation Hospital Dún Laoghaire, Dublin spoke about 'Rehabilitation: The Nursing Perspective'; and Prof Kurt L. Johnson, Dept of Rehabilitation Medicine, School of Medicine, University of

Washington, spoke about 'Combating the challenges of cognitive decline with specific reference to MS'.

The remaining weekend was geared towards people living with MS.

The conference featured numerous workshops and therapies, a rehabilitative devices and adaptations fair, and of course the gala dinner and MS National Awards ceremony, at which the awards for MS Person of the Year, MS Volunteer of the Year and MS Carer of the Year were presented. There was as usual a major social element to the whole event, with entertainment provided in the evenings and plenty of opportunities for attendees to mingle, chat and exchange ideas.

In his address to the conference, Allen O'Connor, MS Ireland Chairman and person with MS, said the event served as an important reminder to those with MS not to let the condition take over their lives. "It is up to each of us as to how much we allow MS dictate who we are. Always remember that just as there is no fixed type of MS – at any time it can differ in severity, duration and progression – there is also no single answer or solution."

Nominations for this year's National MS Awards came from right around the country via 'MSnews' and the 41 voluntary MS Branches. As always, the winners were judged on their involvement with MS Ireland locally, regionally, nationally and within their community.

All presentations from the conference are on the website in the News section

2008 MS PERSON OF THE YEAR

Mary Horan



Mary Horan

THIS YEAR'S MS Person of the Year found out about her win over the phone, as she couldn't make it to the conference, but she was no less thrilled about the news for that. Mary Horan, a long-time member of the Tralee branch, was diagnosed with MS back in 1991, but remains as upbeat and positive about her life as ever and is clearly delighted to have received the accolade.

"It is such a great honour," she says. "I was familiar with the awards but had no idea I was going to win one. I was shocked in one way but thrilled in another."

Diagnosed with MS at the age of 28, Mary has been a member of the Tralee Branch ever since, serving as PRO for two years during that time. Her partner is Ted Cronin, Branch Chairman, and today she is actively involved in fundraising in conjunction with the Branch's annual walk in Lyracrumpan.

The first signs of her MS appeared late in 1990. "I woke up one morning with blurred vision, and people told me I was staggering a bit although I didn't realise it myself at the time," she says. A subsequent MRI scan revealed Mary's condition.

She has been a wheelchair user for the past nine years, but fortunately Mary's sight remained more or less unaffected until recently when she again began to experience some blurred vision. Her MS has not prevented her from going out to work every day for the past 13 years in a job she loves – as receptionist for Kerry County Council. "They are very accommodating and it is very accessible," she says. "I absolutely love the job; I get to meet people and deal with the public, and it's great to get out of the house. If I were at home all the time, I'd say I'd end up dwelling too much on the MS. When I'm working, I can forget about it for a while."

She says she has had a very positive reaction from people about her win. "People I don't know have been coming up to me at work and congratulating me, which is

'My motto is to take every day as it comes'

really brilliant."

Mary is a relatively well-known face around Tralee not just because of her MS-related activities or her job at the council. Back in the Eighties, she used to DJ in the Abbey Inn and did some stints for Kerry Local Radio. "It's a small place, and people get to know you!" she says.

Among the reasons Mary was chosen as MS Person of the Year is her bubbly personality and the fact that she stays upbeat in spite of the obstacles MS throws in her way. "I try to push myself and to be positive, and I find that helps immensely," she says. "I can have a bad day sometimes but I'll pick myself up and get on with it again. I think you are better off being positive."

She says this award is not just for her, but for everyone at the Tralee Branch and everyone else who goes through everyday life with MS. "It recognises the fact that living with MS is not easy, and it means an awful lot to me. The main thing is to look at the ability, not the disability, and my motto is to take every day as it comes."

MS Volunteer of the Year



FOR ONE MS Ireland volunteer from Cork, this year's national conference will stand out as particularly memorable. Sean Murphy, who has been doing voluntary work for MS Ireland for over 30 years and has sat on the Society's board since 2005, had no idea as he attended the event that he would be named Volunteer of the Year before it ended.

"It was a complete surprise," he says. "As someone said to me, it was the first time I have ever been speechless! When I heard the citation, I said to myself 'that's never me'. It was the Branch [Cork City Branch] that nominated me, and I gave out to them afterwards as I thought there were others more deserving of it."

Announcing the award, Mr O'Connor said: "Not only is Sean a great volunteer, he also offers a great deal of kindness and compassion for members with MS. These traits, combined with his efficiency and good heart, result in a jewel of a person. He is an asset to our organisation."

A volunteer with the Cork City Branch, Sean has a busy diary of MS-related duties. Most days, after he finishes his work at the ESB, he has a few more hours' worth of voluntary jobs lined up. On the evening I speak to him he is preparing to pick up lottery tickets for the Branch's weekly draw, which are sold to raise funds for those with MS in the area.

"I always have something to do to keep me going," he says. "I give all the hours I can but I very much enjoy it. I like organising things and making sure things are done right."

Sean first came in contact with MS when his wife, Josephine, was diagnosed with the condition in 1975, just one year after the couple got married. Now Sean looks after Jo with the help of their sons, John and Kevin.

But the Corkman's history of volunteering actually goes back quite a bit further to when he was a youngster in Blackpool, Cork. "My father did voluntary work in the parish, and he sometimes brought me with him to collect money. So when he got cancer, he told me to keep it up for him, and that's what I did for the next few years."

After his wife was diagnosed, Sean found out that the local MS Ireland Branch was looking for church-gate collectors. "I was on the committee by 1980 and haven't looked back since," he says. "We have a fantastic bunch of people in Cork, and the Branch gets good support from the Regional Office."



Sean Murphy, Allen O'Connor and Mary O'Boyle

2008 MS Carer of the Year

It can take a lot of hard work and dedication to look after a person with MS, and those that do it must be recognised for their support and determination.

Mary O'Boyle, this year's MS Carer of the Year, is not only carer to her brother, Brendan, who has MS and requires 24-hour care and supervision, but is also primary carer for her mother, Annie, who requires full care.

An active member of the South Mayo Branch, Mary accompanies Brendan to functions and events organised by the Branch such as weekends away in Galway, Christmas parties, shopping trips etc.

But her selflessness doesn't end with her family – along with offering help to Brendan, Mary also offers assistance to other members. Whether it's with getting on and off the bus, feeding or going to the bathroom, Mary is always willing to lend a hand.

Indeed, this is a woman who puts others before herself. Recently, she reduced her paid working week to four days so that she could meet the demands that caring for two family members have placed on her.

MS Ireland Chairman, Allen O'Connor, said of her at the awards: "She is an exceptionally caring and giving person and most deserving of this award."

Home sweet home



MS Care Centre staff and representatives pick up their EIQA award at the awards ceremony 2009: (l-r) Niamh Sweeney, MS Care Centre Administrator; Lorna Mitchel, Board Member, MS Ireland; Irene Collins, Managing Director, EIQA; Mary O'Grady, MS Care Centre Community Employment Programme Supervisor; and Mary Blake, MS Care Centre MS Specialist Nurse

THE MS RESPITE Care Centre has always been a shining light in MS Ireland's arsenal of services. The beautiful 'home-away-from-home' has always been a place of peace, relaxation and therapy for all those who have stayed there over the years. The centre provides short-term respite care and therapy services to people with MS and other neurological conditions.

MS Ireland is dedicated to developing services to meet the changing needs of the MS community. Over the past year a number of schemes and developments have been introduced. These include completed accreditation from EIQA, redesign of the dining room, FETAC training and the reintroduction of the Saturday intake day.

The most significant development has been the introduction of the MS Specialist Nurse Programme. The innovative programme gives residents an opportunity to speak to the centre's new MS Specialist Nurses and avail of a comprehensive nursing assessment. The specially trained nurses can talk through any issues the person may be having with treatments, symptoms, access to services or any other issue that is impacting on health or quality of life. The aim of the programme is to empower people with MS to manage their own health and interventions.

Lorraine Lenihan is one of the MS Specialist Nurses and says that the programme is an opportunity for people to talk openly about any issues they may be experiencing.

"The programme gives the client the opportunity to have a comprehensive assessment from head to toe. It gives the resident a chance to ask questions, discuss concerns and allows all the professionals in the Care Centre to work together to address identified issues or concerns. The assessment is totally optional and it is very much led by residents. Some may just want information about something in particular, like continence management, while others avail of the full assessment."

Along with the MS Specialists Nurses the centre's Occupational Therapist, Physiotherapist and General Nurses form part of the team involved in the programme. This multi-disciplinary team use their collective expertise to assist clients in addressing issues of concern. The team produce a report for clients, which outlines recommendations and possible interventions.

Respite is the core function of the Care Centre and residents are encouraged to use it as a place of rest and relaxation. The MS Specialist Nurse Programme may be a great benefit to residents, but it is optional and residents are free to use all existing services regardless of participation on the programme.

If you would like to learn more about the MS Specialist Nurse Programme call Lorraine or Mary at 01 490 6234.

Awarding excellence

The MS Care Centre was celebrating recently when it picked up an award at the EIQA National Quality and Excellence Awards. To the credit of all the Care Centre staff, the awards recognise the provision of quality services in light of completion of one of EIQA's certified programmes. Over the past 18 months, staff at the MS Care Centre have completed the 'Committed to Excellence' programme. This programme has brought many positive changes to the Centre.

EIQA's National Quality and Excellence Awards celebrate the commitment and achievements of all nominated bodies. The gala awards ceremony is attended by more than 800 people each year.

MS Ireland would like to offer huge congratulations to everyone involved.



Pauline pictured celebrating her win with all her family and below with Deirdre O'Brien Ray, Shop Manager

A deserving winner

MS CHARITY SHOP volunteer Pauline Smyth was crowned Volunteer of the Year in the Irish Charity Shop Association Awards 2009. The awards recognise the outstanding achievement of volunteers who work in the 200-plus charity shops around Ireland. Pauline beat off stiff competition from charity shop chains like Oxfam, Age Action and the Irish Cancer Society. She has volunteered at the charity shop in Bray, Co Wicklow for 17 years.

She says of her win, "I couldn't believe I won. Deirdre, the manager of the shop, asked if she could put me forward but I only said yes for the craic; I never thought I'd even be considered. I had the most wonderful day at the awards and people have been so good congratulating me about the award. The awards ceremony was also extra special as all my nine children were able to make it, and for the first time in 18 years we have a family photo."

Deirdre O'Brien Ray, manager of the MS Ireland Charity Shop in Bray, composed the following profile of Pauline for the initial application:

"Pauline Smyth is 83 and a half years old (the half is very important to her) and has become a leading light in the shop and an integral part of its everyday running. She is a well-known figure in the town and well-loved by the scores of customers that she has helped over the years.

"Originally involved in setting up the shop, Pauline became the first shop volunteer, working two afternoons a week for eight years. For the past nine years Pauline has worked every Saturday morning. Hail, rain or snow, she is at the shop at 10am sharp ready for work. The only time she takes a break is for the month of November, when she travels on her own to visit her sons in Boston and returns with presents for all her friends in the shop.

"Pauline's long-lasting contribution to MS Ireland is all the more impressive when you hear her personal story. In 1970, Pauline's life took a tragic turn when she was widowed while pregnant with her 10th child. Her husband and eldest daughter were killed in a road traffic accident. She says her positive attitude, sense of humour and her 'fags' and coffee have kept her going. She has a remarkably upbeat attitude which she brings to the atmosphere in the shop.

"For a person of her years she has an amazing capacity for change, with a practical 'can do' approach to any task she undertakes. She has a wonderful sense of humour and can turn any dull atmosphere into a cheerful situation with her dry wit and unique one-liners.

"Pauline touches so many people's lives. She is the face of the MS Charity Shop in Bray and we are very lucky to have her."



All the staff and volunteers in MS Ireland, and in particular the Bray shop, would like to extend a huge congratulations to Pauline and thank her for being such a great ambassador for the Society.

On song

Musician Mark Gilligan has written a new song about living with MS, and even Barack Obama is listening. **Gareth Naughton** reports

A NEW SONG written and recorded by musicians with MS is giving a new insight into the impact of the condition on the thousands diagnosed every year.

Dublinman Mark Gilligan's 'The Lodger Inside of Me' is becoming something of a global anthem for those with MS, and he hopes it will go some way to helping improve lives.

"If I could change one little thing, even a small little thing, it would be an amazing achievement. I just have that positive outlook," says Mark.

Following a series of incorrect diagnoses over the course of a year, Holland-based Mark was finally told that he had MS in 2003. His initial reaction was disbelief and a refusal to accept what was happening but, he says, he quickly realised that the condition affected not only him but his wife and children, and that they would all have to pull together to support each other.

The condition had progressed to a stage last year where Mark's neurologist said that he would be in a wheelchair within six months. He started taking Tysabri and the very opposite happened.

"I am running around, and I haven't done that for years. I am back playing golf again," he says.

The lyrics of "The Lodger Inside of Me" are not MS specific – the condition is not named at any point – and with good reason. Mark was inspired to write the song while on holidays in France shortly after hearing the news that his close friend, the late, great Ronnie Drew, had been diagnosed with cancer. The experiences of another friend, Eurovision-winning songwriter Shay Healy, who is battling Parkinson's disease, also provided some inspiration.

"I wrote in such a way that it was not about self-pity. It is about how I accepted MS myself – it is like your mother-in-law arriving with her bags and she just won't go away. It is a lodger that comes into your life and just won't leave," says Mark.

Mark established musicianswithms.net to meet other musicians in a similar boat. Through that he came in contact with American songwriter Linda Storey, who was diagnosed over 31 years ago and is now paralysed from the neck down. "She blew me away, what a spirit," he says. She invited Mark and his band, the John O'Gods, to perform at some MS



'It is about how I accepted MS myself – it is like your mother-in-law arriving with her bags and she just won't go away'

benefits in her home town of Colorado.

While there they, along with Ms Storey's band, were invited to the studio of Grammy-winning producer John Macy, where they recorded a version of 'The Lodger Inside of Me'.

"It was a case of being in the right place at the right time. It turned out wonderful, thanks to Macy," he says.

Ms Storey is also active in lobbying for the rights of people with disabilities, and while Mark was in Denver, she brought him along to the US National Multiple Sclerosis Society's headquarters for an impromptu performance. The Society has embraced the song wholeheartedly, making it its anthem and available for download on its website.

It subsequently invited Mark to perform the song at its convention in Chicago last November. The timing could not have been better – he was in the Windy City in time to take part in the celebrations following Barack Obama's victory in the presidential election. Mark had already had his own moment of Obama magic during the summer.

"Obama was doing an interview on CNN and I could hear my song playing in the background. It was amazing," he says.

'The Lodger Inside of Me' is available at www.myspace.com/legendarymarkgilligan or by logging on to the National MS Society (US) website, staging.nationalmssociety.org.

TOP TIPS

for fundraising in a recession

AS THE VAST majority of us tighten our belts in these difficult economic times, the voluntary sector has also been feeling the pinch. Understandably, many people are feeling tempted to cut back on their donations, and charities such as MS Ireland have seen a downswing in moneys coming in. However, there are many ways that you can beat the recession while supporting MS Ireland. Paul Collins, Fundraising Manager, MS Ireland, gives his top tips for fundraising on a budget:

- 1. Get active** – if you can't afford the gym this year but want to remain active and fit, then why not get a group of friends together and plan to participate in a run or marathon? MS Ireland can provide you with a calendar of charity runs and marathons around the country for 2009.
- 2. Encourage your company to get involved** – organisations that allocate time and resources to corporate social responsibility (CSR) generally have happier and more productive employees. Many organisations are now adopting a Charity of the Year, channelling their efforts into one cause and focusing mainly on one charity for the year. If a company adopts a charity there's a variety of different ways they can support it, including putting on various fundraising events. Also, charities like MS Ireland run their

own calendars of events throughout the year.

- 3. See your money go further** – PAYE taxpayers who donate €250 or more to MS Ireland in 2009 are actually giving much more to the organisation. For every €250 donated by an individual donor, MS Ireland can reclaim the tax paid on that donation. If you're paying tax at a higher rate, €250 is actually worth €431 to MS Ireland. If you're paying at the standard rate, €250 is worth €313 to the Society. By doing this MS Ireland can reclaim thousands of euro from the Revenue Commissioners at no extra cost to the donor. You will need to fill in the CHY2 Cert, available from MS Ireland or the Revenue Commissioners.
- 4. Give your time/expertise** – if you've been let go from your job, have just retired, or have some spare time on your hands, MS Ireland could use your help. Its Branches are always looking for volunteers to fundraise and help with events. The National Office in Ballsbridge, Dublin is also looking for people to help with various tasks, whether that's helping to cover its busy reception, helping out in its fundraising department or charity shop, or acting as a driver.
- 5. Entertain with a difference** – you



can put on an excellent conference or training event and help a charity at the same time by holding your events at the MS Care Centre in Rathgar, Dublin. The Care Centre has modern conference and training facilities.

- 6. Have a good clean out** – we've all been overrun with material objects in recent years, and having a good clear out can be good for the mind. You can clear your wardrobe or get rid of old bric-a-brac and donate to MS Ireland's Bray charity shop (01-2861913).
- 7. See the world while fundraising** – MS Walks are a fantastic way for you to see the world while raising money for people with MS. This year trekkers are travelling to the Camino de Santiago, Peru, Cuba and Nepal. You can have a life-changing experience on a number of levels.

■ When doing your tax returns this month remember to return your CHY2 form to MS Ireland.



Actor Patrick Stewart at the Bram Stoker Cloak Run Launch in Trinity College with Natasha Duffy of MS Ireland's Walks Department

Cloak Run for the Count

THE BRAM STOKER Society recently launched its 2009 Cloak Run in Trinity College with Star Trek Enterprise Captain Jean Luc Picard, aka actor Patrick Stewart. The Cloak Run spans 5km around Bull Island, Dublin, and can be completed by individuals and teams in a number of categories.

The Cloak Run takes place on the May Bank Holiday with half the proceeds coming to MS Ireland. If you want to get involved contact the fundraising team on 1850 950 650 or fundraising@ms-society.ie.

The Bram Stoker Society operates the Bram Stoker Dracula Experience in Clontarf, which is 'a uniquely different, most interesting, brilliantly entertaining, interactive, educational and very scary adventure based on the life of Bram Stoker, his great vampire creation, Dracula, and horror in general'. The Society is raising money to purchase the house Bram Stoker was born and lived in.

Portmarnock ICA Support MS Ireland

THE PORTMARNOCK IRISH Countrywomen's Association (ICA) raised €3,635 over the last 12 months through a series of quizzes, cake sales and other fundraising events as it adopted MS Ireland as its Charity of the Year.

Mary Coonan, President, Portmarnock ICA, says: "I was bowled over by the support for our fundraising efforts in 2008. We are delighted to raise this fabulous amount of money for the work of MS Ireland for people affected by multiple sclerosis in Dublin and throughout the country."

MS Ireland wishes to thank all those in the Portmarnock ICA and those who supported all the fundraising ventures.



Paul Collins, Fundraising Manager of MS Ireland, presents Mary Coonan, President of the Portmarnock ICA, with a certificate as an acknowledgement of thanks for the donation of €3,635

Get your armbands on

THE ANNUAL MS Swim will be taking place on Sunday, 26 April in the Marian College Swimming Pool, Lansdowne Road, Dublin 4. The swim has been running for over 15 years and is an excellent opportunity to have fun with your friends or colleagues, while raising essential funds for MS Ireland.

Each team/individual completes a half-hour sponsored swim. You may choose to enter as an individual and swim for the half hour alone, or you can enter a team and swim as a relay. If a large number of people from your group wish to swim, you may enter as two or more separate teams. We welcome all kinds of

swimmers, from beginners (armbands accepted!) to the experienced. Each swimmer will be supplied with sponsorship cards from MS Ireland.

If you want to get involved call Jane on 1850 650 950 for more details and a sponsorship card.

A sweet deal for people with MS



Pictured (l-r): Mary O'Connor, Rita McGlade, Kate Sweetman (jumping), Ann Marie James (lying down), Laura Ward and Ann McCullagh



Bernie Woodcock, who has MS, ran a spectacular Gala Ball sponsored by Amble Developments on 22 August 2008. Pictured (l-r): Clyde Davidson, Jaqui Monahan, Martin Lennox, Ciaran Woodcock, Bernie Woodcock, Paul Collins and Kirstie Collins

THE SWEETMANS ARE a family of action. When Noel Sweetman's sister was diagnosed with MS he turned the distressing news into an inspirational campaign that has seen him, his sister Bernie, friends, family and strangers raise a staggering €124,000 for MS Ireland.

"We didn't expect MS to come to our family's door but when it did we felt the best way to deal with it was to do something positive," says Noel. "Our aim was to raise money but it was also about creating awareness, getting people involved and building a sense of community around living with MS and supporting MS Ireland."

Noel's first fundraising venture took him all the way to Kilimanjaro when he trekked with a group in 2007. Planning to raise €10,000 Noel, Bernie and their band of fundraisers managed to reach a whopping €40,000.

"I couldn't believe it. I was delighted that the bad news Bernie received was counteracted in some way by the positive and generous actions of all those who donated or helped raise the money. We was so inspired that we felt we needed to do more."

Noel's sister, Bernie (Woodstock) was

diagnosed with MS in 2005. The diagnosis happened fast, the shock was acute but with the family trait of 'taking action' Bernie also jumped on the fundraising wagon, organising events, collecting money and support along the route.

Meanwhile, their brother Michael and his wife Sarah organised a midsummer fundraising barbecue.

Bernie then organised a glamorous Gala Ball. Held in Carnegie Court Hotel in Swords in August, 240 people were treated to dinner, dancing and an auction, first prize being a trip to see Chelsea play a home game.

"We couldn't believe the response," says Bernie. "We were and continue to be bowled over by the support of our communities. It has really showed us how good people are and how willing they are to support positive action."

Noel and his friend Gary Owens decided to get a group together to run the New York City Marathon for MS. Twenty-five friends and family members took part in the marathon, each paying their own way.

Noel says of their fundraising ventures: "We enjoy it immensely and get so much out of it."

'It has really showed us how good people are and how willing they are to support positive action'

MS Ireland would like to extend heartfelt thanks to Bernie, Noel and their generous family and supporters. It is only with the dedication, enthusiasm and hard work of people like this that MS Ireland is able to reach out to the thousands of families in Ireland living with MS. Monies raised will be used to fund a number of services and resources in our respite Care Centre.

The Multiple Sclerosis Society of Ireland would like to thank the following businesses for supporting the MS Reach for a Star Appeal this Christmas, in association with Blanchardstown Centre. Their generous support has helped to enable those affected by MS to live the life of their choice to their fullest potential.

Top Star

McCann FitzGerald

Gold Star

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www.researchandmarkets.com

Silver Stars

Gazette Group Newspapers **élan** **Business Plus** **MANLEY CONSTRUCTION**

Bronze Stars

biogen idec **DUGGAN STEEL GROUP** **Bayer HealthCare** **Bayer Schering Pharma** **Highbury Lane PROPERTIES LTD** **Grafton Merchants ROI** **whitespace Publishing Group**

Listings

- * Lalor O'Shea * Northern Trust Ireland * The Printed Image Premiums
- * Fournier Laboratories Ireland Ltd * Carroll Food Services Ltd * Eurospar Drogheda
- * Greenstar Ltd * Portobello School * Greencore Group * Support Direct * EI Electronics
- * C & G Engineering Ltd * Orbigo (IT) Solutions Ltd * Bon Secours Hospital * PPAG Ltd

All companies' stars will be on display in Blanchardstown Centre

MS Ireland wishes our supporters and all those affected by MS a very Merry Christmas and a Happy New Year. The MS Society of Ireland is the largest nationwide charity dedicated to supporting people with MS and the many people who share their lives. Why not get your company involved in the MS Reach for a Star Christmas Campaign. Call 01 6781600, email cherylg@ms-society.ie or log onto www.ms-society.ie for more information or to make a donation.



SUPPORT OUR SERVICES

The services of MS Ireland rely heavily on the generous support from our many members, friends and supporters. We would be grateful if you could become a regular supporter or even ask your friends and family to get involved. All monies are used to services directly to the MS Community.

Here's my regular gift to help continue the fight against Multiple Sclerosis.



* Your Gift could go further – at no extra cost to you.

If you pay income tax, a gift of €21 each month could be worth an additional €14 each month to MS Ireland. Please tick the box below if relevant to your circumstances:

- I am not a PAYE taxpayer
- I am Self-Assessed/Self Employed (Tax can be refunded to you)

Charity number CHY 5365

YES, I would like to support the MS Ireland with a Regular Gift.

I would like to make a monthly Direct Debit gift of:

€7 €14 €21* other €



Instruction to you Bank/ Building Society

Originators ID Number: 303335

Bank/Building Society Name: _____

Bank/Building Society Address: _____

Branch Sort Code: _____ Account No: _____

Name of Account Holder(s): _____

For Office use only

Instruction to your Bank or Building Society: I instruct you to pay Direct Debits from my account at the request of MS Ireland. The amounts may be debited on various dates. I understand that MS Ireland may change the dates and amounts only after giving me prior notice. I shall duly notify the Bank in writing if I wish to cancel this instruction. I understand that if any Direct Debit is paid which breaks the terms of this instruction, the Bank will make a refund.

Signature: _____ Date: _____

Telephone: _____ Email: _____

To make an instant donation call **Lo Call 1850 930 329** or visit **www.ms-society.ie**

On high ground

Pat Dwyer's latest book of poetry deals excellently with MS

SOMETIMES, HAVING MS can lead you down an interesting direction in life, and for long-time MS Ireland member and person with MS Pat Dwyer that route was one of writing. In October, Pat launched his latest book of poetry and prose, titled 'Above Ground and Breathing'.

Diagnosed with MS in 2000, Pat is a committee member of the Offaly Branch. He is originally from Tipperary but now lives in Portlaoise with his wife and family.

He is no stranger to writing, and has so far penned three books: the first being 'Thurles to Cuba with Love', published in 2002 and the second 'Bright Clouds', published in 2004. In 1998, he also won an award in the Dún Laoghaire/Rathdown International Poetry Competition.

Following on from his highly-acclaimed 'Bright Clouds', where Pat expertly blended scientific fact and personal

experience, 'Above Ground and Breathing' is a book of poetry and prose that focuses on memories Pat made while travelling in Spain, Cuba, New York and many other foreign lands.

He says: "I have always had an interest in poetry. I write as it's like self-therapy. I never considered my work as academic or anything but it helps me get my frustrations out. The publication has been written specifically to heighten awareness and to raise funds for MS."

This is a very interesting book that provides an open and witty insight into Pat's travels. It also deals excellently with the issue of MS.

Very kindly, Pat has agreed to give all proceeds of the book directly to the Offaly MS Society.

To order a copy of 'Above Ground and Breathing' please contact Pat on 057 8620387 or 086 326 9622.



LETTER TO THE EDITOR

Dear Editor,

I wish to pass on some useful information to your members. I have MS and in order to enjoy our holidays as much as possible my wife and I have fully adapted our apartment in Playa Flamenca, Spain. We would be delighted to rent it out as an accessible apartment to others who may have difficulties finding suitable holiday accommodation. A number of wheelchair users have stayed in the apartment and they found it fully met their needs.

It is a two-bedroom apartment on the second floor, overlooking a communal pool. It is accessible by ramp outside and a lift inside. It is only a five-minute walk to the largest commercial centres in the area, hosting an abundance of bars, shops, restaurants, supermarkets and banks, which we have found to be very wheelchair accessible. Playa Flamenca is well known for its abundance of blue flag sandy beaches/coves with lovely walks. The nearest large town is Torrevieja, which is only a 10-minute drive/bus ride away, and boasts a new outdoor shopping centre, an aquapark and a beautiful promenade.

I am more than happy to help people source any mobility equipment, as we have used some on our own trips. I can be contacted on 087 6539699 for more information.

Don Coen, Donegal

Editor's note: If you have an accessible apartment or wish to recommend an apartment, resort or hotel in Ireland or abroad, please write to me. In the next 'MSnews' we would like to do a feature on holidays.

MS Information Day in Cavan

AN MS INFORMATION Day was recently held in the new Irish Wheelchair Association (IWA) Centre in Cavan. It was an opportunity for people to meet with the local HSE professionals to find out about the services available for those with MS and their carers.

The IWA Driving Instructors provided a vehicle demonstrating the various options in car adaptations and they also took the opportunity to look at some of the vehicles being used and advise accordingly. For many, the whole area of registering on the Disabled Drivers Scheme and finding out if a grant is available can be very confusing. It was therefore very helpful to have people pointed in the right direction around the



Motorised Transport Grant and getting an adaptation. In addition to this, the Physiotherapist met new people immediately so that they could be referred for treatment. The Occupational Therapist gave advice on all aspects of living safely at home and on accessibility issues, while the Speech and Language

Therapist, the Incontinence Nurse and a specialised Nurse in MS from St Christopher's Centre were all available to speak in private to individuals.

There was information on accessing respite facilities including St Christopher's in Cavan, the MS Care Centre in Bushy Park and Cuisle, run by the IWA in Roscommon.

There was a very relaxed atmosphere – everyone was made to feel comfortable and the Centre made it easy for people to mix and talk. It was an excellent day and showed good collaborative working with the HSE and voluntary sectors involved in ensuring good practice for those with MS.

An Offaly good run

The Offaly Branch of MS Ireland would like to thank Jim Dolan and all who supported the Ballingar run held in September to raise funds for the Branch. Pictured are some of the runners, supporters and Offaly Branch committee members.



Carnew Heritage Day

NORTH WEXFORD MS Branch would like to thank the dedicated committee of the Carnew Heritage Club, and add an extra special word of thanks to all the new younger members, for organising another successful Heritage Working Day in aid of the Branch, KARE, Tinahely and the new Carnew Scouts Troop.

The North Wexford MS branch would also like to thank all the tea ladies, those who did baking for the event, and anyone who helped in any way to make the day such a success. A special thank you to the land owners for making their land available. All money raised for the Branch is spent locally on people with MS.



Teeing off



Above: Donegal Branch Chairman Muriel Perry, centre, stands with the winning ladies team of the Ballybofey and Stranorlar Golf Classic, held in aid of MS Ireland. Below: the winning men's team were employees from Tinneys Oil, Letterkenny, pictured with Muriel Perry and Veronica Gillen of the Donegal Branch.



North West Community Employment Scheme

June McHugh, who works on the Community Employment Scheme in the North West, presented a cheque for €1,000, which she raised through a raffle in her local area, to the North West Regional Office. The money was greatly appreciated and will go a long way towards supporting the Office.



Some of the Community Employment Scheme employees at their Christmas dinner in Letterkenny.

MS Ireland
THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

TRIBUTE

Mary Coogan RIP



The members and friends of the North Wexford Branch of MS Ireland would like to extend their deepest sympathies to the Coogan Family, Ballinglen, Co Wicklow on the recent death of their mother, Mary.

Mary and her extended family, including her grandchildren, have been staunch supporters in fundraising down through the years and raised thousands of euros in helping to support the Branch, which is very much appreciated.

Mary was a lady who had a smile for everybody and was very interested in handcrafts such as crochet and needlework. She always appeared at social events in good humour and had a friendly word for everybody. She enjoyed all events and it was a credit to her family that one of them was always there to care for her. She will be sadly missed by all those who knew her and for her wonderful warm spirit, which she shared with everybody.

Extract from a local tribute:

'Her manner was gentle and refined, she was unfailingly courteous, and was interested in people and their welfare. May she rest in peace.'

Blessed among women

Cork City stalwart Frank Carey sits among all the beautiful 'ladies' of Brown Thomas, Cork, who ran the Cork City Marathon in October in aid of the Branch. Thanks ladies!



Festivities in Leitrim



Members of the Leitrim Branch enjoying the festivities at their Christmas dinner on 14 December. A great time was had by all.



Mobile money

Kate Beattie, far right, presents a cheque for €500 to members of the Donegal Branch. Kate raised the money by recycling unused mobile phones.

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The Drive Grip is ergonomically adjusted and easy to unload and put on.

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The Carony chair has substantial and adjustable armrests as standard.

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The wheelchair frame is vertically variable with 115mm to be conformed for different car models and ground conditions when you dock into the car. You can vertically adjust the Carony with an easy manoeuvrable crank on the side of the wheelchair frame.

SUBSTANTIAL WHEELS

The substantial wheels are compact and suitable for all environments.

SECURITY FIRST

The chair has side support and a headrest. It is also crash-tested with the actual chair in the car and meets the security requirements from all the major car manufacturers. Carony is equipped with security functions to minimise risks when loading and unloading. Carony Transport Wheelchair is CE marked.

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The anatomically constructed chair has good side support, sway-back support and correct sit angle.

FREE FOOT PASSAGE

The U-shaped wheelchair frame gives free passage for the passenger's feet when the frame is removed.



Celtic notes



Paschal O'Toole of Kilinaskully fame presents a cheque to the Cork City Branch from proceeds generated by the concert held in University College Cork featuring the Celtic Divas and the Garda Band. From left: Garda John O'Halloran, Marina O'Carroll from RTÉ, Paschal O'Toole, Dolores Murphy, Martina Byrne and Josephine Murphy.

Cork City Person of the Year



Dolores Murphy of the Cork City Branch was awarded its MS Person of the Year 2008. Dolores, right, celebrates her award with her sister, Paula, and her mother, Josie.

MSNEWS ON HOLIDAYS



In the last 'MSnews' we published an image of our beloved 'MSnews' enjoying the scenery in Greece and asked other readers to send in similar pics. We received this from Pat O'Dwyer in Limerick:

"My wife, myself and 'MSnews' are just back from a two-week holiday in Tenerife. Here I am reading 'MSnews' while relaxing on my mobility scooter at the beach. As you can see we enjoyed great sunshine and were out all the time. Can't wait to go back next year."

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- Professionally Insured To Carry Out Sales Repair & Hire
- C.E. Approved Products of High Quality (New or Reconditioned)
- Mobility Dealer of The Year With Thousands of Satisfied Customers
- Trade-ins Accepted Ask About Our Watertight Guarantee
- Nationwide Service

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