

August 2009

East Coast Area News

Welcome to your Summer / Autumn 2009 edition of the MS ECA News

Another eventful few months have passed in the office. A big thank you to Cathy O'Brien, who has now moved on to pastures new, for the enormous amount of work she did on the various events that we've held. A special mention must be made on her smooth and efficient management of the Getting the Balance Right Project, which was no easy task! We wish her all the very best in the future. We will hopefully see the return of Jennifer and Barbara to the office during the Autumn.

Inside this edition you'll find articles and information on a wide variety of topics. Also included are details of our Autumn courses—the new Brain Gym evening course as well as our ever popular yoga courses. Dates and details of upcoming coffee mornings can be found on the back page. If you have anything that you'd like to include in our next edition, or would like information on MS in general, please do not hesitate to contact us at the regional office.

My Experience with MS

On a visit to San Francisco in the summer of 2000 while walking down by pier 36 having watched the seals play in the bay I noticed for the first time my left leg began to drag. And after some time I had to stop and rest. Having sat on a bench for about 5 minutes I was once again able to make it back to the car.

My first thought about the incident was that it could have been a disc problem as I had a history of low back pain many years ago. So on my return to Ireland I spoke to my GP and he referred me to an orthopedic surgeon, who in turn referred me to a neurologist, who after a brief examination said he believed I might have MS.

I was admitted to Tallaght Hospital, and after various tests the diagnosis was confirmed that I had primary progressive MS. This, needless to say, came as quite a shock, but as he said at the time 'it won't kill you but you just grow old quicker.

Ten years later and I can say he was wrong. Yes, the MS has not improved but I can still play croquet, snooker, and swim. I even occasionally fly a small aircraft.

Yes, I get tired (but if I live within my limits, life goes on.) My foot drags and I use a walking stick.

But all that is behind me now. About 6 months ago I got a magazine called 'Momentum' from the USA, in which I saw an ad for a product called 'Walk Aid'. It was a collar which fitted around the leg just below the knee which sends an electrical impulse down to the foot, which caused it to lift, so avoiding the dragging of the shoe along the ground. Now I can walk almost normally, using a stick only if I am going into crowds, just for balance.

Recently I was in New York and friends were amazed at the improvement in my walking. So if anyone has the condition called 'drop foot' this appliance is worth a try. Since using the appliance I have not fallen once.

By John Treanor

Beat the Blues with MS BBQ's

MS Ireland is encouraging all our friends, supporters and anyone interested in food to host or come along to a BBQ in aid of MS Ireland this summer. We are raising money in aid of MS research, which we hope will lead to better treatments, interventions, management and ultimately a cure for MS. Organise your own BBQ with friends and family over the summer, kindly asking them to give a donation to MS Ireland instead of the usual bottle of wine or flowers. Each host will get a pack including posters, sponsorship card, balloons and a selection of recipes. Every person running a BBQ will be entered into a draw for afternoon tea for two in The Fours Seasons Hotel, Ballsbridge.

MS Ireland will also be hosting a family-friendly BBQ on Sunday 30th August in The Thomas Priory Hall of Bewleys Hotel, Ballsbridge. Running from **2pm to 6pm**, tickets cost €40 per person or €99 for a family ticket (2 adults and up to 3 kids). Food, beverages, games and entertainment will be provided. Anyone for a go on the bouncy castle? To book a ticket call Áine or Jane on 01 678 1600 or email bbq@ms-society.ie

Our BBQ will also be a '[Happy Birthday MS Walks](#)' as we celebrate 21 years of trekking the globe with our fabulous walkers. If you are one of the thousands who have strapped on boots for MS Ireland come along to our pre-BBQ reception and reminisce about the days of walking and nights of fun.

To book a Walkers ticket contact Cathryn or Natasha on 01 678 1600 or walks@ms-society.ie

Potential New Oral Drug Performs Well In Trials

An article taken from our internal intranet site...

Cladribine is a potential oral therapy for relapsing-remitting MS. It is commonly used to treat types of leukemia. It is effective against a type of immune cell, called T cells, which makes it a promising candidate in autoimmune conditions such as MS. One late stage, phase III study called CLARITY (Cladribine Tablets in treating MS orally) has recently finished and compared oral Cladribine against a placebo in more than 1300 people with relapsing remitting MS. Early results released from this trial have revealed a reduction in relapses by up to 58%. More results relating to the reduction in MS lesions and disability progression are expected to be released later in 2009. An extension of this study will also be conducted to evaluate the longer term safety and effectiveness of oral Cladribine. The current situation on the safety and effective of oral Cladribine is being accessed. The drug maker Serono (Geneva) announced that oral Cladribine has been designated by the U.S. Food and Drug Administration (FDA) as a 'Fast Track Product'. This designation should speed up its future review by the FDA if the drug proves to be safe and effective in treating MS.

An Introduction to Brain Gym

On September 8th we commence an evening programme entitled "**Brain Gym**" which will be held in the Stillorgan Park Hotel over four consecutive Tuesday evenings - September 8th, 15th, 22nd & 29th. (There was a Brain Gym taster workshop at the Spring Feast in Athlone last April, about which we received overwhelmingly positive feedback).

Brain Gym is a highly specialised branch of Educational Kinesiology which facilitates the brain and the body to work more efficiently together to make thinking and learning, movement and creativity easier. This programme will be run by Pádraig King of Brain Gym Ireland, a Brain Gym /Educational Kinesiologist.

Brain Gym facilitates the process of achieving our personal goals at our own rate and using the best of our resources. Educational Kinesiology works to re-educate the brain and body to work more efficiently together enabling us to work and play closer to our true potential. Brain Gym is a program of physical movements that enhance learning and performance in ALL areas.

We look forward to seeing you in September as this programme promises to be educational and good fun! More information can be found in the flyer and application form included with this Newsletter.

MS Conference 2009

On the 25th - 27th of September MS Ireland will host its Annual Conference in the Clayton Hotel, Galway. The weekend will be a mixture of information, education and enjoyment for health professionals and people affected by MS.

Friday 25th will be an information seminar for health professionals. **Saturday 26th** will be the conference for people affected by MS. Attendees will be treated to an exciting mix of presentations in the area of rehabilitation. The highlight will be the presentation of the results of 'Getting The Balance Right', our exercise based health promotion and research programme. A choice of workshops will also be run on Saturday.

The day will close with the official Launch of 'Getting The Balance Right' report by Minister Eamon Ó Cuív. This will be followed by a Gala Dinner and the presentation of our Annual Awards. Awards will be presented for Person of the Year, Volunteer of the Year and MS Carer of the Year. The nominations for this year's Annual Awards closed on the 17th July 2009.

A products fair will be run on **Sunday** morning showcasing a variety of rehabilitative devices and adaptations. The day will also include a Council meeting for all voluntary Branches and the 2009 Annual General Meeting of the Society.

For further information please [download](#) our booking form from www.ms-society.ie Please return by 7th August to Carmel Owen, Clayton Hotel, Ballybrit, Galway. Visit www.clayton.ie or call 091 721900

Annual General Meeting—The tenth Annual General Meeting of the Multiple Sclerosis Society of Ireland will take place in the Clayton Hotel, Ballybrit, Co. Galway on Sunday, 27th September at 11.00 a.m. 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.

Every registered member of MS Ireland 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 18th September 2009.

Board Vacancies—Can you help us? MS Ireland is looking for interested and enthusiastic people to sit on its board. The skills and expertise we would like to see represented on our board are those experienced with MS either directly or through caring for a family member, finance, government policy, nursing (senior level), property, personnel, communications and management. If you have the skills and experience we need and are interested in MS, disability rights, community based support and governance in the not-for-profit sector you could be the person we are looking for. A panel of interested people is being established and candidates will be selected for election. If you are interested please contact Alice McKeon, PA to CEO, MS Ireland, 80 Northumberland Road, Dublin 4 or email alicem@ms-society.ie.

Disease Modifying Drugs May Improve Cognitive Function

Glatiramer acetate and beta interferon may have a positive effect on cognitive symptoms of multiple sclerosis according to recently presented research.

Results of an observational study to evaluate the long term effects of glatiramer acetate or beta interferon on cognitive impact on MS were presented at the European Neurological Society meeting in June. Dr Falauntano, principal investigator, summarised the results of the study by suggesting that immunomodulatory treatment may have a positive effect on cognitive function but stated that longer term follow up is required to confirm these findings.

Pam Macfarlane, Chief Executive of the MS Trust (UK) said "This is interesting data, the MS Trust is very aware of the impact of cognitive deficits on the lives of around half of all people who live with MS. We have recently launched StayingSmart to support people in managing and understanding the cognitive impact of MS."

Cognitive symptoms, which include effects on memory, planning and organisational skills and concentration, are experienced by around half of all people living with MS.

StayingSmart is a web-based resource designed for people who want to know, or know more, about how MS can affect thinking and aims to:

- support learning about cognition in MS
- build confidence in managing cognition in MS
- facilitate sharing of knowledge about and experience of cognition in MS

For further information please log on to www.stayingsmart.org.uk

Getting the Balance Right 2008/2009

We have been very busy all year working on "**Getting The Balance Right**", our Nationwide Activity/ Exercise and Health Promotion programme.

We have had over 135 people linked to intervention programmes, including Physiotherapy, Yoga & Fitness, and depending on remaining funding, an additional 25 people will start a programme in September 2009

The University of Limerick Physiotherapy Department have commenced collating the research data, this report will be launched in September 2009 at our National Conference held in the Clayton Hotel, Galway, by Minister Eamon O Cuiv.

If you have any questions about the project please contact us.

Who Cares for the Carer?

A new free information guide aimed specifically at the more than 161,000 family carers in Ireland has been published by Home Instead Care. It examines the role of caregiving from the carers point of view, offering insights and information on coping with the stresses the task inevitably brings.

Caregiver stress can manifest itself in a wide range of ways, emotionally and physically, including disturbed sleep, headaches, weight fluctuation, fatigue, anxiety and mood swings. It is vitally important for family caregivers to recognise the signs and take steps to deal with stress before it becomes a major problem for the caregiver themselves or for the person they look after.

It is estimated that one in four Irish adults is currently caring for a parent or relative, with almost half of this group providing care for their spouse. Another group, often unrecognised, are the large numbers of children under 18 years who are caring for a parent or sibling. While caring can be a very rewarding and bonding experience, the role is often demanding, exhausting and stressful which can lead to feelings of isolation and depression.

'Running on Empty' acknowledges and explains emotional and physical responses to providing care. It covers topics such as how to recognise signs of stress and offers coping mechanisms that can be taken to avert potential future problems. A free copy 'Running on Empty' can be obtained from any of the 15 Home Instead Senior Care Offices in Ireland or by calling 1890 930 013.

Research News

- A study published in the journal Archives of Neurology has found that smoking may increase disability and progression in MS. The study, based at Harvard Medical School, looked at 1465 people with MS. Of the study participants 788 had never smoked, 428 were ex-smokers and 257 were current smokers. Surveys looking at progression and disability using the Expanded Disability Status Scale as well as MRI scans were carried out on all participants for a period of more than three years.

Current smokers had significantly increased disability at the beginning of the study and were more than twice as likely to have primary progressive MS than non-smokers participating in the study. Furthermore, the study found that current smokers were more than twice as likely to progress from relapsing remitting MS to secondary progressive MS in the time that the study was being conducted. MRI scans also revealed that number of lesions increased in the group of participants that smoked compared with the non-smoking group of participants. Authors of the study stated, "Although causality remains to be proved, these findings suggest that patients with MS who quit smoking may not only reduce their risk of smoking-related diseases but also delay the progression of MS." Other genetic and environmental factors that may be linked to MS are not considered in this study and will need to be looked at in more detail before firm conclusions can be drawn about the role of smoking in MS.

- Scientists in Madrid have released findings of their research into the use of an epileptic drug on trigeminal neuralgia, a facial pain condition sometimes experienced by people with MS. 65 people took part in the small study which found that those who took the drug on its own (39 people) and those who took it in addition to their current pain medication (29 people), the pain intensity decreased by 50% over the 12 week period. Larger scale studies are being considered. Read more on our website www.ms-society.ie

The Sunshine of Your Smile

There are many reasons why smiling is good for you – here's a few fabulous facts that are bound to bring on a beam!

Smiling is good for your health! Smiling increases the production of endorphins (natural painkillers) and serotonin (a mood-regulating hormone), increases infection-fighting antibodies; enhances the effectiveness of T-cells; lowers blood pressure; helps relaxation; enhances respiratory function; and fires up different parts of the brain! Research by the University of Michigan has found that optimistic people have a different biological make-up; they are healthier and live longer.

Do we smile because we're happy or are we happy because we smile? The Facial Feedback Theory claims that emotion can be regulated by behaviour, particularly by facial expression. So if you're having a bad day, slap on a smile and see if your mood lightens up.

Chocolate without the calories! According to the British Dental Health Foundation, a smile gives the same level of positive stimulation in the brain as eating 2,000 chocolate bars!

I can hear you smile! – Research has shown that when a person who is speaking on the phone is smiling, the person listening can actually sense it. In fact, many telemarketing companies require that their telemarketers sit facing a mirror to remind them to smile as they speak.

Be careful who you frown at! 86% of people are more likely to talk to strangers who smile. Who wants to meet a frowning person? *"Wear a smile and have friends; wear a scowl and have wrinkles."* George Eliot

The best facelift ever - Smile and your eyes lighten up. Frown and your eyes darken. It takes less muscles to smile (17) than it does to frown (43). *"A smile is an inexpensive way to change your looks."* Charles Gordy

Smiling is good for your career! Research has shown that people who smile a lot are 12% more likely to get promoted.

Smile to yourself – In ancient China, it was believed an inner smile is like basking in love; you become your own best friend. *"Living with an inner smile is to live in harmony with yourself."* -Mantak Chia

"Today, give a stranger one of your smiles. It might be the only sunshine he sees all day."
H. Jackson Brown Jr

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Calendar of Events

- September Brain Gym Every Tuesday 8th—29th Sept. (4 weeks)
Yoga Stillorgan Park Hotel from Mon 14th Sept. for 8 weeks
Yoga Shankill (St. Anne's) from Fri 18th Sept. for 8 weeks
- October 7th Coffee Morning for PwMS & Family Members / Carers
TBC
21st Coffee Evening for PwMS & Family Members / Carers
TBC
- November 4th Coffee Morning for PwMS & Family Members / Carers
TBC
- December 11th Carers Christmas Lunch

All events will be confirmed by post –some with this Newsletter mailing

Save the Date!

The Southside Partnership, Dun Laoghaire Rathdown County Council, RAPID and Community Platform are running a joint event on Tuesday 13th October 2009. 'Celebrating the Arts' will be a cultural event for people with disabilities, as part of Social Inclusion Week. Artwork, dance, music etc. will all be included and everyone with a disability is invited to exhibit or join in. More details can be obtained from Alison or Sandra in the Southside Partnership (01 2090610), or Rebakah at Dun Laoghaire Rathdown County Council (01 2047324).

Mums and soon to be MumsTell us your experience

Are you interested in talking about your experience of maternity and early childhood services in Ireland? Do you have any of the following?

- Blind / vision impairment
- Deaf/ hard of hearing
- Physical disability
- Experience of mental health services

Are you a member of any of these groups? Are you over 18 years of age and pregnant or have had a baby in the past two years?

If the answer is yes, then the School of Nursing and Midwifery in Trinity College would like to hear from you. The study will provide valuable information about women's experiences and may improve maternity and childhood services in Ireland. For further information, please contact Denise Lawler, 086 3789758 / lawlerde@tcd.ie. This study is funded by the National Disability Authority and has been granted ethical approval from the Faculty of Health Sciences, Trinity College, Dublin.

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