

February 2010

East Coast Area News

Hello and welcome to the Spring Edition of your newsletter from the East Coast Area.

2010 brings many changes to our Region. Jennifer has returned to the team after her period of leave. She will be working three full days a week. Geraldine who has been with us for the last year will be staying in this region. Barbara has resigned from her post. We welcome Jennifer's return, are delighted that Geraldine is staying with us and we wish Barbara well!

At the end of January, due to financial restrictions, we moved to a smaller office in Delgany. We will continue to offer the same services and cover the same geographical area of South East Dublin and East Wicklow. As usual, if we are not in the office when you phone, please leave a message on our answering machine or drop us an email. Our new address and telephone number is:

MS Regional Office, Sunnyside House, Delgany, Co. Wicklow.

Our new phone number is : 01 2871704.

As always, our helpline, MS Contact, is available on 1850 233 233 Monday to Friday from 10am to 5pm and on Tuesday and Thursday evenings from 6:30pm to 9:30pm.

We would love to hear from you with comments about any article you read in this Newsletter. Also don't forget to update us with news, events, etc, that might be of interest. We realise that with the down turn in the economy, it has been a very hard year for many. Here's to a more healthy, happy and prosperous 2010 for all.

New Branch launched for East Wicklow

The Chief Executive of MS Ireland, Anne Winslow, speaking at the recent launch of the new East Wicklow Branch of the society, was enthusiastic about the numbers who attended the occasion at the Glenview Hotel. Outlining some of the benefits of a larger local branch, she highlighted the strength in numbers for better local social supports and for lobbying. She hopes that all the members of the society and others in the area will soon join the branch. Former chairman of the organisation, Louise Wardell, a resident of Ashford, who chaired this inaugural meeting, paid tribute to the Bray Branch for its efforts over the years and its generosity in merging with and supporting the new and larger venture. MS Community Worker in the East Coast Area, Geraldine Dunne, spoke to the group about the services provided by the society and reported on the positive research results just published on the benefits of physiotherapy and exercise programmes for people with multiple sclerosis, hoping that the new branch will support the regional effort in organising more of these locally.

Mark Mitchell, of Greystones, was unanimously elected chairman of the committee. Persis Quin, well known to all members from Bray and further afield, has agreed to undertake the role of treasurer. Persis has been volunteering for the society for over 40 years and her fundraising achievements have been amazing. Amongst the thirteen man committee elected is cllr Simon Harris, whose interest in disability issues has been well publicised and who recently helped the issue of the unsuitability of the pavements in Greystones town for wheelchairs to be tackled and resolved. He was warmly welcomed.

A surprise free raffle of a weekend for two at the Clayton Hotel, Galway, to launch the branch was won by a thrilled Anne Tallant.

The first meeting of the East Wicklow Branch of the MS-Society took place on the first weekend of November, when among the items on the agenda for discussion were the dates for social events and the question of numbers of people with MS in the area who are already in need of housing extensions to enable them to continue to live in their own homes, and for which there have been no grants available for two years already. This is not just a local problem for the new committee; numbers are being collated nationally for the initial step in lobbying to address this need. If you need to contact Mark Mitchell, please email him at mark.mitchell8@gmail.com or by text on 087-2453193



Pictured are Doreen, Helen, Eileen & Bridget at the launch of the East Wicklow Branch in the Glenview Hotel.

All Good Things...

...must come to an end

In September of this year, I made the difficult decision not to return to my job as Community Worker with MS Ireland. I have thoroughly enjoyed the last five years of meeting all the wonderful and varied people in this region and even further afield. There have been both challenging times and wonderfully satisfying times

Most of all, I have been genuinely touched by the calibre of individuals I have been fortunate enough to meet. As a person with MS myself, I have had the experience of being a service user AND a service provider. This has helped me to understand just how difficult it can be at times to live with MS and how frustrating it can be when services are scant. I have been privileged to meet an eclectic bunch of fellow PwMS whose combined intelligence, humour and kindness is unsurpassed. Equally, I have witnessed an enormous amount of dedication and commitment from front line staff trying to learn more about this mysterious illness and to do their utmost to provide an effective and compassionate service to people with MS and those close to them.

The last five years has left me with an indelible feeling of inspiration and optimism for the future. These are exciting times for research into MS and for breakthroughs in treatment. I always felt that hope is the biggest commodity that a person with MS can possess. With hope comes strength and a determination to accept the illness while still being able to live life moment to moment. I want to thank people for the honesty and trust they have shown me in my role as Community Worker with MS Ireland. I wish everyone an abundance of joy and hope for the coming year.

Barbara Western

True hope dwells on the possible, even when life seems to be a plot written by someone who wants to see how much adversity we can overcome, True hope responds to the real world, to real life; it is an active effort - Walter Anderson

Getting the Balance Right Update

Many of you are by now familiar with Getting the Balance Right, our national physiotherapy and exercise programme which initially involved a research study. Up to September 2009 it was estimated that 16,520 separate intervention sessions took place over the course of the programme all over the country and this number continues to grow. The preliminary findings of the Getting The Balance Right study are now available to download. [http://ms-society.ie/uploads/File/GTBR%20Findings%20Launch%20booklet%20\(2\).pdf](http://ms-society.ie/uploads/File/GTBR%20Findings%20Launch%20booklet%20(2).pdf)

SOME KEY PRELIMINARY FINDINGS

- The average duration of current physiotherapy intervention in a variety of settings is three hours in a three month period.**
- 23% of the total number of people who at most use a stick improved their levels of fatigue to the extent that they moved them from a clinical measurement of 'fatigued' to 'non-fatigued'. This was reported in 27% of those on physiotherapy programmes, 18% of those on yoga programmes and 23% of those on instructor-led gym programmes. Other studies have shown that 93% of people with MS reported fatigue as a limitation.
- 25% of participants in the group physiotherapy programme moved from a high to a low risk of falling. Other studies have shown that 64% of people with MS report at least two falls per year, affecting confidence in walking and social participation.
- 5% of the controls in the group who at most use a stick experienced a relapse, while only 1% of those on physiotherapy led programmes experienced a relapse.
- Those in the group physiotherapy programme for people who at most use a stick experienced a 19% reduction in the level of fatigue. Participants noted improvements in energy, ability to recall information and time needed to complete tasks.
- Those who use a rollator or two sticks and participated in one-to-one physiotherapy programmes experienced a 16% reduction in levels of fatigue.
- Those in the physiotherapy led programmes for people who at most use a stick experienced a 15% reduction in the psychological impact of MS. Participants noted improvements in their general attitude and happiness.
- Those who use a rollator or two sticks and participated in group physiotherapy experienced a 20% improvement in their balance.
- Wheelchair users receiving a standard physiotherapy programme, experienced improvement in the impact of MS. Carer burden was also reduced for this group.

- Those who use a rollator or two sticks in the yoga programmes experienced a 20% increase in their walking ability, improving the distance they were able to walk in six minutes.

We *hope* to be in a position to continue with some physiotherapy classes in 2010.

If you are interested in participating please contact the regional office on (01) 2871704

FURTHER INFORMATION AND RESOURCES

- We have published two guides for people with MS offering an arrange of information around exercise and practical techniques to use at home. MS and Fitness and Everybody Stretch are available to download from our website: http://ms-society.ie/uploads/File/MSandFitness_canadianbooklet.pdf
http://ms-society.ie/uploads/File/everyone_stretch_canadianbooklet.pdf

MS 'blood blockage theory' tested

By Michelle Roberts—Health reporter, BBC News

US scientists are testing a radical new theory that multiple sclerosis (MS) is caused by blockages in the veins that drain the brain. The University of Buffalo team were intrigued by the work of Italian researcher Dr Paolo Zamboni who claims 90% of MS is caused by narrowed veins. He says the restricted drainage, visible on scans, injures the brain leading to MS. He has already widened the blockages in a handful of patients. The US team want to replicate his earlier work before treating patients. Experts welcomed the research saying it was important to confirm the basic science before evaluating any therapy.

MS is a long-term inflammatory condition of the central nervous system which affects the transfer of messages from the nervous system to the rest of the body. " This is not something patients can expect as a treatment now. This is experimental work and is being tested " - a spokeswoman for the MS Society.

The Buffalo team, led by Dr Robert Zivadinov, plan to recruit 1,100 patients with MS and 600 other volunteers as controls who are either healthy or have neurological diseases other than MS. Using Doppler ultrasound, they will scan the patients to see if they can find any blockages within the veins of the neck and brain. If they can prove Dr Zamboni's theory of "chronic cerebrospinal venous insufficiency", they say it will change our understanding of MS.

Rewriting science

Margaret Paroski, who is chief medical officer at Kaleida Health, where the Buffalo researchers are based, said the work could overturn prevailing wisdom that the damage in MS is predominantly the result of abnormal immune responses. "When I was in medical school, we thought peptic ulcer disease was due to stress. We now know that 80% of cases are due to a bacterial infection.

"Dr Zivadinov's work may lead to a whole different way of thinking about MS." Dr Zamboni, of the University of Ferrara, believes the blockages are the cause rather than the consequence of MS and that they allow iron from the blood to leak into the brain tissue, where it causes damage. He has performed procedures similar to angioplasty to unblock the veins and get the blood flowing normally again. He claims this "liberation procedure" can alleviate many of the symptoms of MS and is due to publish his findings in the Journal of Vascular Surgery. In an interview with CTV News in Canada he said: "I found the evidence of narrowing - narrowing of the veins just in MS patients. "I'm fully convinced that this is very, very important for people."

Early days

Kevin Lipp, an MS patient from the US, has been symptom-free since being treated by Dr Zamboni. He said: "It's only been 10 months. If nothing happens in the next two to three years, we'll know it's working." The BBC has heard anecdotally of other surgeons in Europe testing out the same treatment. The MS Society said more research was needed to see if this was an avenue that should be explored further. "This is not something patients can expect as a treatment now. This is experimental work and is being tested. We need to know more about its safety and effectiveness." Helen Yates, of the MS Resource Centre, said: "There is no doubt that this area warrants a great deal more study. "This could represent a completely novel approach to MS research which, if proven to be relevant, could be a "sea change" in the understanding of the mechanisms involved in the condition."

CTV, a Canadian TV channel featured Dr Zamboni's work on their news programme on 21 November 2009. You can watch the video or read the report on their website - here is the link:

http://www.ctv.ca/servlet/ArticleNews/story/CTVNews/20091120/W5_liberation_091121/20091121?hub=TopStoriesV2

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Computer Equipment

A person in our region has a Packard Bell Computer, Scanner & Printer to give away. Also included is a brand new desk & chair. Please contact the office for further details.

Other news...

Dr Alasdair Coles, Neurologist and MS Researcher, who spoke at our World MS Day seminar in Cork, was filmed at Addenbrooke's Hospital, Cambridge on 20th August 2009. There are seven parts to the video. Dr Coles gives an outline on each of the following therapies; Tysabri, Cladribine, Fingolimod and Alemtuzumab, in relation to effectiveness, safety and convenience for persons with multiple sclerosis (MS).

He discusses the importance of expert advice in the decision making process and the status on licensing, safety, effectiveness and convenience for each of these drugs. To see this video, please log on to http://www.mssociety.org.uk/support_and_services/audio_and_video/video/awareness_talks/current_and_emerging_therapies/current_and_emer.html

The US drug regulator, the US Food and Drug Administration (FDA) has 'refused to file' a license application for Cladribine, an oral disease modifying drug for relapsing/remitting multiple sclerosis. The drug regulator usually issues such a response when it finds applications to be incomplete. In a press release, the president of the drug manufacturer, Merck Serono, said: "The company will work closely with the FDA to fully understand FDA's concerns and define a path forward for a successful resubmission of this application at the earliest point in time." FTY720 (fingolimod), a second oral disease modifying drug, was submitted to regulators in America and Europe in December. Decisions on these applications are awaited.

From MS Trust UK website

Programme of Events 2010

February/March	Yoga PwMS Stillorgan Park Hotel
February/March	Yoga PwMS St Anne's Resource Centre, Shankill
17 th February	Information & Support PwMS Stillorgan Park Hotel
25 th February	Information & Support Carers Stillorgan Park Hotel
April/May	2 x Physiotherapy Groups MS Care Centre - Rathgar
April/May	2 x Physiotherapy Groups Open Door Day Centre, Bray
23-25 th April	Spring Feast Weekend – PwMS & Carers or Friend Sheraton Hotel, Athlone
May	Information & Support – PwMS Arklow Bay Hotel
May	Information & Support – Carers Arklow Bay Hotel
26 th May	World MS Day
29 June	Carers Day
1st July	Teenagers Adventure Break
7 th July	Younger Persons Fun Day
July	Information & Support - PwMS Avoca, Kilmacanogue
July	Information & Support – Carers Avoca, Kilmacanogue

A few useful links:

- Young people with a parent with MS (and X Factor fans!). Pop singer Oritse Williams (whose mum has MS) from the band JLS has made this video for the MS Society UK to talk about his experiences:
http://www.mssociety.org.uk/support_and_services/audio_and_video/video/oritse_williams.html
- Learn more about cognitive difficulties in MS and build confidence in managing them.
Visit the MS Trust UK's Staying Smart website:
<http://www.stayingsmart.org.uk/>
- For those who spend most of their day sitting down, Are You Sitting Comfortably?, a new self-help guide to good posture in sitting, is available to download or read online
<http://www.mstrust.org.uk/shop/product.jsp?prodid=290>

If you have any advice or information on MS and your own experience, and would like to share it with others through our next newsletter, please contact us at the office.

Disclaimer:

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