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WOODHAVEN HOUSE

NEWSLETTER SPRING 2012 - Vol 1 Issue 1



Dear Readers,

The MS North West Therapy Centre exists to enrich the lives of people with Multiple Sclerosis by providing essential services and support to patients and their families.

In this first issue of MS Newsletter we give you an overview of Multiple Sclerosis - description, signs and symptoms and treatments. We also set out the services we offer at the MS Centre and how to access them.

There is also news on recent and upcoming fundraising events and how you can get involved.

We have updates on the exciting new venture - Woodhaven House, a state of the art Respite Centre on the 1st Sea Road in Sligo.

This is your Newsletter and we hope you find it interesting and informative. We welcome any news items and stories and suggestions/comments from you, our readers, if you have anything you would like to be included in the next Newsletter, please hand it in to Bairbre at Reception.

Tamara Gormley (Manager)

DESCRIPTION, SYMPTOMS AND TREATMENT OF MS

Description

Multiple Sclerosis is a nerve disorder caused by the destruction of the insulating layer surrounding neurons in the brain and the rest of the body. When the myelin is destroyed, nerves no longer communicate properly with other parts of the body. Multiple Sclerosis causes a wide variety of symptoms and can affect vision, balance, strength, sensation, coordination, and bodily functions.

Research shows that women are almost twice as likely to get Multiple Sclerosis as men, especially in their earlier years. Multiple Sclerosis rates are higher in the United States, Canada and Northern Europe. On the other hand, Multiple Sclerosis is very rare among Asians, North and South Americans, Indians and Eskimos.

Multiple Sclerosis is an autoimmune disease, caused by an attack by the body's own immune system. For unknown reasons, immune cells attack and destroy the myelin sheath, which speeds transmission and prevents electrical activity in one cell from short-circuiting to another cell. Disruption of communication between the brain and other parts of the body prevent normal passage of sensations and control messages, leading to the symptoms of Multiple Sclerosis. The demyelinated areas appear as plaques, small round areas of grey neuron without the white myelin covering.

The progression of symptoms in Multiple Sclerosis is correlated with the development of new plaques in the part of the brain or spinal cord controlling the affected areas. Because there appears to be no pattern in the appearance of new plaques, the progression of Multiple Sclerosis can be unpredictable.

Despite considerable research, the trigger for this autoimmune destruction is still unknown. At various times, evidence has pointed to genes, environmental factors, viruses, or a combination of these.

The role of an environmental factor is suggested by studies of the effect of

migration on the risk of developing Multiple Sclerosis. Age plays an important role in determining this change in risk — young people in low-risk groups who move into countries with higher Multiple Sclerosis rates display the risk rates of their new surroundings, while older migrants retain the risk of their original home country. One interpretation of these studies is that an environmental factor, either protective or harmful, is acquired in earlier life. The risk of contracting the disease later in life reflects the effects of their earlier environment.

Symptoms at a glance

Multiple sclerosis symptoms may be single or multiple and may range from mild to severe intensity and short to long in duration. Some symptoms may include:

- ◇ visual disturbances,
- ◇ limb weakness,
- ◇ muscle spasms,
- ◇ loss of sensation, speech impediment, tremors, or dizziness,
- ◇ depression,
- ◇ manic depression,
- ◇ paranoia, or uncontrollable urge to laugh and weep

Types of Multiple Sclerosis?

There are different clinical manifestations of multiple sclerosis. During an attack, a person experiences a sudden deterioration in normal physical abilities that may range from mild to severe. This attack, sometimes referred to as an **exacerbation of multiple sclerosis**, typically lasts more than 24 hours and generally more than a few weeks (rarely more than four weeks).

About 65%-80% of individuals begin with **relapsing-remitting (RR) MS**, the most common type. In this type, they experience a series of attacks followed by complete or partial disappearance of the symptoms (remission) until another attack

occurs (relapse). It may be weeks to decades between relapses.

In **primary-progressive (PP) MS**, there is a continuous, gradual decline in a person's physical abilities from the outset rather than relapses. About 10%-20% of individuals begin with PP-MS.

Those beginning with RR-MS can then enter a phase where relapses are rare but more disability accumulates, and are said to have **secondary-progressive (SP) MS**.

How is Multiple Sclerosis treated?

There are many issues for the patient and physician to consider in treating multiple sclerosis. Goals may include:

- ◇ improving the speed of recovery from attacks (treatment with steroid drugs);
- ◇ reducing the number of attacks or the number of MRI lesions; or
- ◇ attempting to slow progression of the disease (treatment with disease modifying drugs or DMDs).

An additional goal is relief from complications due to the loss of function of affected organs (treatment with drugs aimed at specific symptoms).

Most neurologists will consider treatment with DMDs once the diagnosis of relapsing remitting multiple sclerosis is established. Many will begin treatment at the time of the first multiple sclerosis attack, since clinical trials have suggested that patients in whom treatment is delayed may not benefit as much as patients who are treated early.

It is important for patients to talk to their doctor before deciding to go on therapy since DMDs differ in their uses (for example, one DMD may be used for slowing progressing disability but not for treatment of the first attack of MS; another DMD may be used for

reducing relapses but not for slowing progressing disability).

Finally, utilizing support groups or counseling may be helpful for patients and their families whose lives may be affected directly by multiple sclerosis.

Once goals have been set, initial therapy may include medications to manage attacks, symptoms, or both. An understanding of the potential side effects of drugs is critical for the patient because sometimes side effects alone deter patients from drug therapy. Patients may choose to avoid drugs altogether or choose an alternative drug that may offer relief with fewer side effects. A continuous dialogue between the patient and physician about the medications is important in determining the needs for treatment.

Drugs known to affect the immune system have become the primary focus for managing multiple sclerosis. Initially, corticosteroids, such as prednisone (Deltasone, Liquid Pred, Deltasone, Orasone, Prednicen-M) or methylprednisolone (Medrol, Depo-Medrol), were widely used. However, since their effect on the immune system is non-specific (general) and they may use may cause numerous side effects, corticosteroids now tend to be used to manage only severe multiple sclerosis attacks (that is, attacks leading to physical disability or causing pain).

References: <http://www.medicinenet.com>

Editor's Note: *The above article attempts to describe all the symptoms of MS. It is important to know that every individual case of MS is different, and your symptoms do not necessarily have to follow this pattern. If you have any queries, ask your consultant and your health care professionals.*

Remember: there is strength in knowledge.

FUNDRAISING NEWS

The Fundraising Committee at the MS Therapy Centre do tremendous work in providing funds to support the MS Centre and the Woodhaven House Project (see next page).

The members of the Committee are:

Chairperson: Vincent Hunt

Treasurer: Liam Hunt

Secretary: Paula Lahiff

PRO: Paula Moran

Members: Margaret Robinson, Maria McLoughlin, Bridie McLean, Pascal Morrison, Mary O'Connor, Columb McBride.

The following events took place recently:

Jigs and Reels: Paula Moran and Dominic McLoughlin did us proud in the recent Jigs and Reels organised by the Lions Club and Radisson Hotel, raising €7,000.

An Seisuin Mor: Maria McLoughlin and her friends organised a 12 hour traditional music session at Rosses Point with all sponsorship going to the MS Centre. This event raised over €3000.

Barn Dance: This fun event took place in Higgins of Culfadda on St. Patrick's Night, raising over €1000.

The Sligo Rose of Tralee Competition and The Mayor's Ball

have both nominated the MS Centre are one of the beneficiaries of their recent fund-raising events.

Table Quiz: This event held in the Harp Tavern was a very successful fundraiser recently.

Bag-Pack at Dunnes Stores: This took place on Holy Thursday with the assistance of students from the local secondary schools.

Cake Sale and Car Boot Sale: This event took place on Easter Sunday in Cloonloo.

Church Gate and Street Collections :

Collections take place several times a year to back up fundraising events and many thanks are due to all those people who give of their time and effort to raise much needed funds for the MS Therapy Centre. If you or your family/friends can spare even a few hours to assist us with fund-raising events and/or collections, please let any member of the Committee or Bairbre at Reception, know.

Upcoming events:

Fun Cycle: 16th June

Women's Mini-Marathon: 4th June

Sponsorship cards available from Bairbre at Reception.

FUNDRAISING PHOTOS



Presentation of cheque from Longford Cycle Club



Members of Fundraising Committee



Presentation of cheque from Teeling Classic Car Club



Time for a hot cuppa!



The Wren Boys—do you recognise anyone?



Betty and Chris - smiling for the camera!

MORE PHOTOS



Paula and Maria at Christmas Dinner - Cheers!



Longford Wheelers - cheque from Eamonn Considine



Moonlight Walkers!



Vincent and Sr Mary - Smile you're on camera!



Ready, Steady and they're off!



Enjoying a few drinks at Christmas Dinner

PHOTOS FROM ANNUAL SOCIAL



Fun on the Fundraising Committee!



Do you recognise these three beauties?



The two Macs



The Barrys enjoying the Annual Social



Aideen and Padraig smile for the camera!



Maria and Pat McLoughlin and Mrs Cullen

SERVICES AT MS THERAPY CENTRE AND HOW TO ACCESS THEM

Hyperbaric Oxygen Therapy

Hyperbaric Oxygen therapy simply means increasing the concentration of just the same oxygen we breathe normally in air. MS Therapy has one of the few HBO Chambers in Ireland.

Physiotherapy

In the MS Therapy Centre, Physiotherapy can be provided both on a one-to-one or group basis. Group sessions consist of Circuit Classes, Mat Classes (floor exercises), Pilates and Hydrotherapy.

Counselling

Giving voice to feelings, thoughts and fears about MS can help to eventually find new and better ways to live with the condition.

Holistic Therapies

Integrative complementary healing including reflexology, massage and bodywork is an inclusive holistic approach to modern health care and is now recognised for its valuable contribution in this field, by its inclusion in current medical training programmes around the world.

Foot Care Clinic

Appointments can be made for foot care.

Lunch

Lunch is provided every week-day at the Centre at a minimum charge.

Family/Carers Group

The MS Centre aims to set up a Family Group for people with MS and their family/carers shortly. This will be a peer support group facilitated by a social worker, and will provide a mix of information, social support and contact with others who are going through the same difficulties. Watch this space!

How to access services

Services at the MS Centre can be accessed by filling in an application form available from reception or from the website. The application form must be completed by your doctor before you can be considered for treatments.

How is the MS Therapy Centre Funded?

The MS Therapy Centre is part-funded by a grant from the HSE, but relies heavily on fundraising and donations to make up the shortfall in funds needed for the provision of services.

(For ways to donate please go to page 11 or see the website:

www.mstherapycentre.ie)

FUN CYCLE FUNDRAISER FOR WOODHAVEN HOUSE—MS RESPITE CENTRE

The MS Centre is delighted to announce that there will be a Fun Cycle Fundraiser on Saturday 16th June 2012, starting and finishing in Sligo.

The route is 150km approx – passing through Sligo – Ballina – Swinford – Charlestown – Sligo.

Individual cyclists and relay teams welcome!

Minimum fundraising amount €100 per individual or €50 per team member. (Teams have to have a minimum of 4 members.)

Registration closes on Friday 11th May (cyclists can join and register along the way).

Registration forms and sponsorship cards available from Nora (087 2195470) or Helen (087 6808707) or from Bairbre or any member of the Fundraising Committee at the MS Centre (071 9144748). We would love,

more than anything, if you could join us on the cycle, however if this is not an option, we would appreciate your support in some of the following ways:

- Print and distribute the Poster, Flyers and the Registration Form (Available from the MS Centre.)
- Send an email to all your contacts



WOODHAVEN HOUSE BEFORE THE REFURBISHMENT

- Update your company's website/ social page with the Poster/Flyers/ Registration Form and details
- Text the details to anyone you think may be interested
- "Like" our status on Facebook: "Respite Centre Cycle"
- Spread the word!

WOODHAVEN HOUSE—an update

In 2009 The MS Northwest Therapy Centre commenced planning for a Respite service as an extension of its services in the area.

They undertook a study of client needs and concluded that there was very little available by way of respite breaks for people with MS other than admission to a local community hospital, or to the acute hospital services.

The fundraising group of the services undertook the task of raising the much need money for the project and in September of 2011 Woodhaven House was purchased as the proposed site for the service.

The house is situated on a half acre site on the First Sea Road approximately 4 kms from Sligo town.

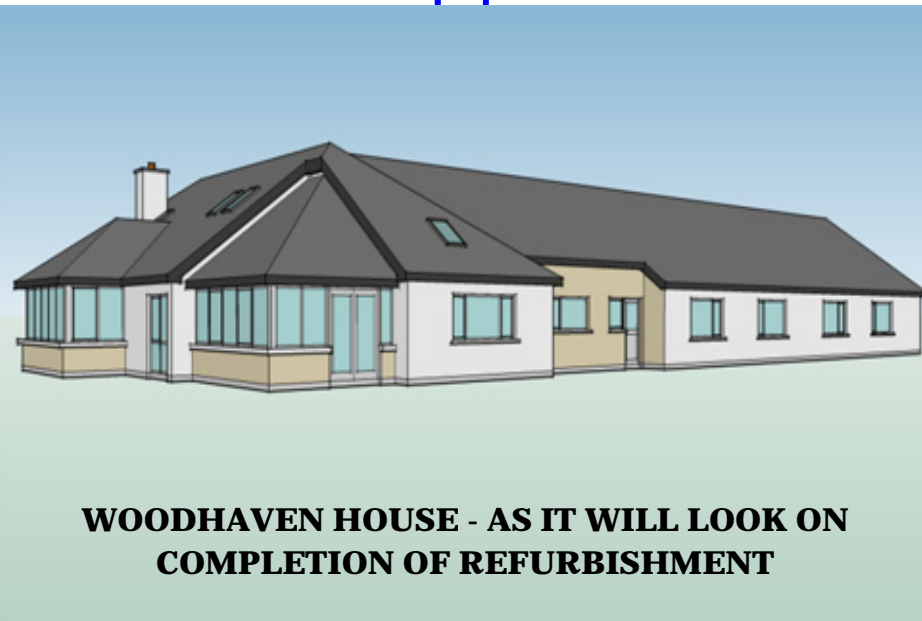
Planning permission for a total revamp of the house was granted in February of this year.

The project is designed to the highest standards of access and comfort for persons with a disability. It will have five fully accessible bedrooms, lounge and sitting room space as well as a treatment room. All bedrooms are en-suite and will be fitted with overhead hoists. There are plans to build a small community facility on the site, with office and meeting room space. This building we hope to share with other groups needing accommodation.

The service has defined respite care as the following:

Respite care is defined as the provision of short-term, temporary relief for those who are caring for others. It is any activity or service of limited duration designed to provide a break for a dependent person and their carer/family. One of the main features of respite

care is that it provides time limited breaks for families and other unpaid care givers in order to support and maintain the primary care-giving relationship. Respite should also



WOODHAVEN HOUSE - AS IT WILL LOOK ON COMPLETION OF REFURBISHMENT

provide a positive experience for both parties which should enhance the quality of their lives and support their relationship.

The Unit when open will offer the following:

- ◇ Attractive and creative person-centred residential/day respite breaks for clients and their families.
- ◇ Increased accessibility to respite breaks for people with a physical disability.
- ◇ Affordability and value for money.
- ◇ Creative forms of respite such as availing of services such as Reflexology, Massage, counselling, physiotherapy etc. (this service to be provided by staff at the present MS Centre)
- ◇ The possibility of attending services of the MS Therapy Centre such as

physiotherapy, hydrotherapy, hyperbaric oxygen while on a respite break.

- ◇ Short stay recuperation, when necessary, following discharge from acute hospital services.
- ◇ Supplement the work of the Neurology team, local PCCC teams and other groups involved in the provision of services to people in the target group.
- ◇ Reduce the incidents, where possible, of unnecessary admissions to acute and community hospitals for respite care.
- ◇ Provide a client-centred value for money service.
- ◇ Allow where possible a situation where the client can be accompanied and possibly cared for in respite by their personal assistant.
- ◇ A state of the art respite unit which is not available outside of Dublin.
- ◇ The service will also offer breaks to families of children with a disability as well as offering family breaks to other family members affected by disability.
- ◇ Efficiencies achieved through cross border working
- ◇ A shuttle bus service between the Respite unit and the MS Centre
- ◇ The local/town bus stop on the road directly outside the house.

The project has its own design team which is lead by Mr Eamonn O'Dowd. This group plan to commence building work on the project in May of this year.

The final design will cost approximately €400,000 to complete: to this end we would like to meet with groups or individuals who are interested in sponsoring pieces of equipment or furniture for the project, or assist in fundraising for this Project.

HOW YOU CAN DONATE TO THIS EXCITING PROJECT

Buy a Brick

Buy a brick for €10 each and have your name inscribed on the Buy a Brick page of the website. (of course you may also remain anonymous if you so wish.)

Donate by PayRoll Giving

Why not ask your employer if you can donate by PayRoll Giving. Payroll giving allows you to donate straight from your wages making it an easy, hassle free way to donate. As it's also tax free it is a great way to make your donation go further without any extra cost to you.

Donate by Electronic Transfer

Ask your bank to set up a weekly or monthly standing order to the MS Therapy Centre.

Tax Relief on Donations

If you are an employer or self-employed, tax relief is available on donations of €250 or more. Please note the charity number for the MS North West Therapy Centre is CHY 10323.

Wedding Tent Cards

If you are getting married, you can opt to give a donation to the MS North West Therapy Centre in lieu of wedding favours. We will provide you with a tasteful tent card to place at each setting. For more information on this idea, please contact MS Therapy Centre Reception.

Will Bequests

Remember the MS North West Therapy Centre in your Will – all bequests will be gratefully received.

Whichever way you choose to donate you can be certain that we are very, very grateful for your support. All donations will be acknowledged.

MEET THE DIRECTORS

Chairperson: Gerry Quinn

Secretary: Pairaic Colreavy

Treasurer: Vincent Hunt

Members:

Seamus Dolan,
Pascal Morrison,
Joe Bradley,
Michael Barrett,
Bridie McLean,
Columb McBride

Management Sub-Committee:

Chairperson: Michael Barrett

Secretary: Mary Henry

Members:

Tamara Gormley
Pairaic Colreavy
Bridie McLean
Gerry Quinn

Building Project Committee:

Project Co-ordinator: Sr Mary Henry

Members:

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Eamonn O'Dowd
Maureen McTiernan
Helen Kilcullen
Vincent Hunt

Legal Advisor:

Eamonn Creed (McDermott, Creed & Martyn)

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Brian Kilfeather (Gilroy and Gannon)

MEET THE STAFF

Manager: Tamara Gormley

Admin Support: Bairbre Moore

Physiotherapists:

Aideen Melanaphy: (Senior Physiotherapist)
Marguerita Ruiz Martinez
Noelle Carroll
Maria Armstrong

Physio Assistant:

Paula Moran

HBO Technician:

Margaret Fallon

Driver/Maintenance/HBO

Brian O'Donnell

Care Assistants:

Sarah Melly
Aisling McLoughlin
Ann Harragon

Social Worker:

Tara Niemeyer

Services Personnel:

Holistic Therapists:

Deirdre Murray
Jackie Hanley

Counsellor:

Sr Mary Gallagher

Foot Care Clinic:

Martina Connolly

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