



# news

THE MULTIPLE SCLEROSIS SOCIETY OF IRELAND

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Autumn 2007



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**EDITOR'S LETTER**



The days may be getting shorter but here in MS Ireland they are becoming busier! With an action-packed year, our staff, volunteers and members show no sign of slowing down on the activities and events taking place all over the country.

Thanks to everyone who came along to the MSLiving Convention in May – the biggest event MS Ireland has ever held was a resounding success. Thanks also to everyone who took part in our election campaign. We hope you will continue to boost this level of raising awareness in your own areas. This will complement the many efforts planned by the MS Ireland staff and Board to ensure the decision makers in the Government and Health Service Executive adequately consider the needs of the MS community.

In this edition of *MSnews*, we look at the area of residential care. While a tough and emotive issue, many people choose residential care as an alternative or better way to maintain health and deal with social inclusion issues. We also take a look at the many policy and legal developments in the area of disability and also explore the often talked about area of neurology.

**TARAGH DONOHOE —**  
Communications, MS Ireland

**COVER STORY**  
Tackling residential care

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**NEWS FLASH!**

MS Ireland is holding its 2007 Raffle Appeal, with the draw set to take place on Monday 19 November. Tickets are just €2 and the first prize is a €3,000 travel voucher from Thomson Travel. A plasma screen TV, cash prize and weekend away are among the runner-up prizes. The Society will also hold a sellers' draw. Please find a raffle book with this edition of *MSnews* and support a good cause. You never know — one of your friends, family or neighbours might be among the lucky winners!

**ADVANCE NOTICE:**

The cover story in the next *MSnews* will focus on the area of physical therapy, including exercise and physiotherapy. We will also look at how accessible our towns and cities are becoming. If you have any contributions, please contact Taragh at MS Ireland.

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**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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# Genetic risk factors for MS identified

**A GROUP OF** international researchers has identified new genetic risk factors for MS. The findings — the first to discover genes conclusively linked to MS — could lead to new treatments for the disease.

The breakthrough results by the International Multiple Sclerosis Genetics Consortium (IMSGC) come after the completion of the largest-ever scan of all genes in the body for MS. The study, which cost just under €3m, points to potential mechanisms causing the disease.

The IMSGC has identified two new genetic variations associated with MS, and two independent collaborating groups have now published papers to confirm one of the gene variations.

Often referred to as an instruction manual, a gene contains all the information needed to make our bodies function. So, we have genes for our eye colour, the size of our ears and nose and so on. Genes will help us make proteins, which in turn help us hear, for example.

With the exception of identical twins, all individuals have their own unique set of genes. While there are 30,000 genes in the human body, these genes are then made up of smaller particles. Brothers and sisters may have similar genes, but all genes are varied, meaning at least one thing about the gene will be different. This is called gene variations. To use words and letters as an example, if you change one letter in a word, you get a completely different word. For example, 'g'roat and 'c'roat mean two very different things.

Gene variations are not necessarily bad, and in certain cases they may actually be good and could protect the body from various diseases. However, sometimes the variation can be bad and could, when combined with lifestyle or other factors, increase the susceptibility to certain conditions such as MS or heart disease.



Dr Stephen Hauser, Professor of Neurology at University of California San Francisco, who worked on one part of the study, notes: "This discovery brings us on to a whole new pathway that could have a very important role in understanding the fundamental mechanisms that trigger MS."

Dr John R Richert, Executive Vice-President, Research & Clinical Programmes at the National MS Society in the US, says the findings could help the eventual prevention of MS.

"By pinpointing genes that elevate the risk of developing MS and other autoimmune diseases, these studies lead us in new directions for both treating and eventually preventing these diseases," he adds.

The genome scan study by IMSGC saw collaborators test some 500,000 individual genetic locations, using the latest technology, a DNA chip. They scanned all of the genes in the human body for

variations that were more commonly inherited by people with MS than those without it. Some 931 'trio families' (those people who have MS but whose parents were unaffected) were screened.

To double-check their findings, researchers then performed a second analysis of other families, individual cases of MS and a control group. In total, more than 12,000 people were tested.

The IMSGC's intense analysis discovered two new genetic variations, both of which show a very significant association with MS. The variations are located in the genes that play an important role in the immune attack that is launched on the brain and spinal cord in those with MS.

Researchers have decided to make all of the data from the gene scan available to the public, in order to assist any further research. This latest study is just one part of a major endeavour over the past two decades to search for genetic links with MS.

# Bundoran Conference 2007

## GETTING THE BALANCE

9-11 November, Great Northern Hotel, Bundoran, Co Donegal

MS Ireland is delighted to invite you to our 22nd national conference in Bundoran, Co Donegal. One of the longest-running events in the MS Ireland services cache, the conference is a mixture of information, education and enjoyment for anyone affected by MS. The conference this year will discuss developments in complementary therapies, symptom management, physiotherapy and MS treatments.



### Provisional programme:

#### Saturday 10 November

- Official opening by Pat Dolan, Local Health Manager, HSE West, Manorhamilton
- Jan de Vries, renowned international complementary healthcare expert, will discuss the role of complementary therapies in living with MS
- Jane Ware, an MS Specialist Nurse in the Wessex Neurological Centre, Southampton General Hospital, will speak about pain and fatigue in MS.

#### Sunday 11 November

- Professor Dame Ingrid Allen, Professor Emeritus of Neuropathology and visiting Professor at the University of Ulster, will discuss up-to-date research and the latest drug treatments available
- Aoife Keegan, MS Ireland Physiotherapist based in the North East, will discuss the role of physiotherapy in alleviating symptoms of MS.

For more information on the conference, please contact the North West Regional office directly on (074) 912 5017.

## 22nd National MS Conference 9-11 NOVEMBER 2007

### North West Region Booking Form Great Northern Hotel, Bundoran

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Tel No: \_\_\_\_\_

Sharing with (Name): \_\_\_\_\_

Branch Name: \_\_\_\_\_

€195 per person sharing (room share basis only)

2 nights B&B + 2 Lunches + Gala Dinner

Please indicate who will pay the balance on your bill

Self \_\_\_\_\_

Branch \_\_\_\_\_

Please tick appropriate box:

\*Your assistance with this information is important so that we can give you appropriate accommodation – Great Northern/Grand Central Hotels

	Yes	No
I Use a Wheelchair Motorised/Manual	<input type="checkbox"/>	<input type="checkbox"/>
I Can Transfer	<input type="checkbox"/>	<input type="checkbox"/>
I Use a Stick/Frame	<input type="checkbox"/>	<input type="checkbox"/>
I Can Walk a Short Distance Only	<input type="checkbox"/>	<input type="checkbox"/>

Specify Any Dietary Requirements: \_\_\_\_\_

I enclose a €70 deposit (per person sharing) to secure my place. Please make cheques payable to MS Society and send to: Catherine Peoples, MS Society, Unit 6, Rossview Business Park, Port Road, Letterkenny, Co Donegal before 12 October 2007.

\*Early bookings advisable\*

Signed: \_\_\_\_\_

# Reminder to register on disability database

**MS is the most reported disability on the National Physical and Sensory Disability Database. MS Ireland is urging people to get their details on it**



**Oliver Durkin, National Vice-Chairman of MS Ireland**

**FOLLOWING THE RELEASE** of the annual report of the National Physical and Sensory Disability Database (NPSDD) earlier this year, MS Ireland is reiterating its call for people with MS who have not registered on the database to do so before next year's report.

The NPSDD is compiled by the Health Service Executive (HSE) areas and managed nationally by the Health Research Board (HRB). It is based on voluntary information, so it is imperative that people with MS come forward and register their details if an accurate picture is to be given to the HSE each year as it plans its funding.

The report of the database for 2006 was released in May and reflects the position in June of last year. MS is the most frequently reported category, with 2,348 cases (9.1%), followed by diabetes (8.1%) and cerebral palsy (7.4%).

Oliver Durkin, who was recently elected National Vice-Chairman of MS Ireland and was involved in data collection in the Sligo area, says people may not realise just how important it is to be

registered on the NPSDD.

"Although being on the database doesn't guarantee a service, it is part of how the HSE plans its services and how it funds them," Oliver says. "I would very strongly encourage people to register. As far as MS Ireland is concerned, having accurate information will strengthen its case when it comes to drawing down funding for MS. If you can prove the service you are giving is of benefit to the user, you are in a much stronger position to get funding. Unfortunately, people are diagnosed with MS all the time and there are new members joining MS Ireland regularly. Some might not be aware of the database's existence."

He adds that, despite its voluntary nature, the database is an important step forward for people with MS. "If you go back three or four years, we didn't even have this database in place. People with learning disabilities got a similar database put in place a few years ago and since then funding shot up for the sector."

The report, based on 25,692 registrations, shows that 90% of people registered were receiving services in June 2006. However, there is still a large number of people waiting to be assessed for a wide variety of services.

Mary-Ann O'Donovan, co-author of the report and member of the HRB, outlined its importance: "This database is the only source of information at a national level about specialist services for people with physical and/or sensory disabilities and is unique in terms of informing service planning. It highlights the areas where services are needed most. This is essential information for health service managers and policy makers."

Indeed, the importance of the database cannot be underestimated, but it is raising the bar when it comes to the issue of provision of services. The challenge facing service providers now is to match the data from the database with actual services, as any information collected will be worthless if the services are not provided to address these.

There are more males (52.8%) than females (47.2%) registered on the database. Over two thirds of all registrations are adults and one third are children (under 18). One in 10 people reported a combination of disabilities, which highlights the need for a more co-ordinated approach to service planning. Oliver stresses that just registering once is not enough — people need to ensure that their record is updated over the years as their circumstances change.

"The nature of MS is that it is a progressive disease, which means that people's requirements change. Their need for therapies and interventions can fluctuate. So it is important not just to register but to update your records so the HSE is aware when new needs arise," he explains.

Not only does the database provide valuable information for the HSE, it can also be a useful source of information for people with MS and their carers.

"It's great to have facts and figures on paper and it is amazing how the report highlights what is available to people with MS — whether it be appliances, aids or therapies," adds Oliver.

People who haven't registered to date and who want to make sure they are included in the next database should simply contact their local MS Regional Office.

# Prague to host international MS event

**PEOPLE AFFECTED BY MS** are being given the opportunity to attend an international event in Prague. On 10 October this year, the Multiple Sclerosis International Federation (MSIF) and the Czech MS Society, in collaboration with the European Multiple Sclerosis Platform, will hold Prague '07 – Living with MS: Today and Tomorrow.

This free one-day event will take place at the Prague Congress Centre in the Czech Republic and is the first of its kind to be held in that country.

The day is expected to be a huge success, with leading international MS specialists presenting talks on the current and future developments of six key areas. Topics to be discussed on the day will

include: how MS is diagnosed; how information is provided; options for treatment; therapy; management; and daily living. All of the talks will be introduced by people with MS.

The audience will also be given the chance to participate as further discussion with questions from the audience will be encouraged. As part of the day, visitors can expect lunch and refreshments.

The event is set to be attended by 600 people affected by MS as well as health professionals, MS society staff and volunteers.

Prague '07 will also mark two other special occasions, with the Czech MS Society celebrating its 15th anniversary



and MSIF its 40th year in existence.

Former Chairman Allen O'Connor will address the conference on Wednesday afternoon.

MS Ireland will be attending the event and will distribute/publish any relevant material.

For further information on the event, please go to [www.prague07.net](http://www.prague07.net).

## Cork celebrates turning 40

**SOME PEOPLE WILL** use any excuse to have a party, and the Cork City Branch is not one to shy away from a good knees-up. The branch's 40th anniversary celebrations are reaching their peak this month, as it holds a glittering night of food and entertainment to celebrate its 40th birthday in style. Some 300 people will attend the celebrations at the Silver Springs Conference Centre on 28 September.

Indeed, this month is a big one for the branch with a number of events taking place, according to Seán Murphy, Treasurer with the Cork City Branch and board member of MS Ireland.

"September is a big month because not only are we celebrating our 40th anniversary, we also have the Cork Ladies Mini Marathon on 22 September and a board meeting on 29 September," he says.

Seán has been a member of the branch for nearly 30 years. He joined in 1978

after his wife was diagnosed with MS in 1975. He recalls the branch's first big bash when, in order to save money, members of the committee served dinners to people with MS.

To celebrate 40 years of hard work and dedication, the Cork City Branch is inviting all past members of the committee to the special night.

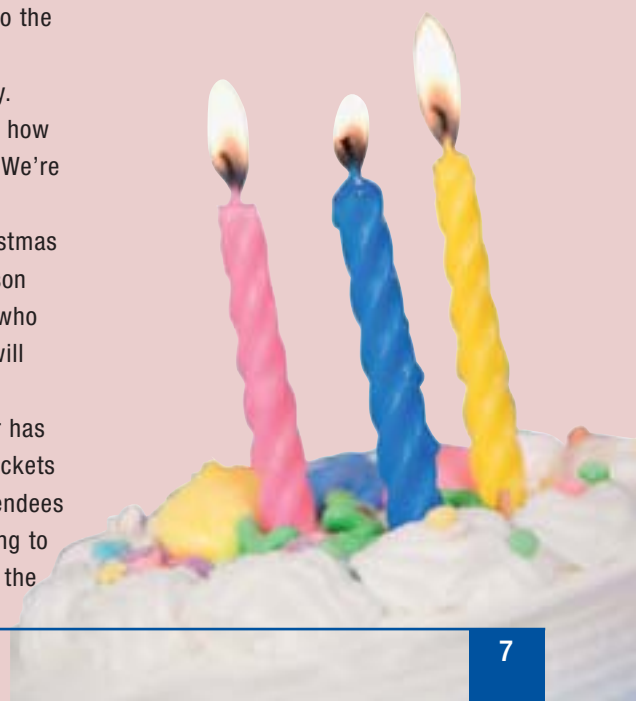
"The Cork branch is one big family. When an awful lot of people find out how well we get on they want to join up. We're there for everyone," says Seán.

Seán assures people that the Christmas dinner will still be held in the Radisson SAS Hotel on 2 December, so those who can't get to the anniversary dinner will have that to look forward to.

Meanwhile, the anniversary dinner has received a lot of sponsorship, with tickets for the night priced at just €20. Attendees can expect music and craic, according to Seán, and a raffle will be held using the

door tickets on the night, with the winner receiving a weekend break in London at the Silver Springs Moran Hotel.

Those interested in attending the 40th anniversary celebrations of the Cork City Branch should contact Seán Murphy on 087 2311990.



# RESEARCH PROJECT SEEKS VOLUNTEERS

**PEOPLE WITH MS** are being invited to partake in a new research project into the disease in Ireland. The study into the epidemiology of MS in Ireland is looking at the incidence and prevalence of MS nationally, as well as differences in various aspects of the disease. With some assistance from MS Ireland, St Vincent's Hospital, Dublin is conducting the study, led by Consultant Neurologists Dr Niall Tubridy, Dr Michael Hutchinson, Endocrinologist Dr Michael McKenna and Research Registrar Dr Roisin Lonergan.

The project involves recruiting up to 1,000 people with MS and a group of controls consisting of a sibling of each involved patient or an age- and gender-matched non-MS patient from the area, explains Dr Lonergan.

Blood samples will be taken from people currently attending clinics in Wexford General Hospital, St Vincent's University Hospital, Dublin and Letterkenny General Hospital, Donegal. Researchers are also hoping to involve a fourth centre in Northern Ireland.

"The project invites people with MS to undergo standard neurological examinations and to have a 30-50ml sample of blood taken," says Dr Lonergan. "The project calls for volunteers with MS of any type living in the counties of Wexford or Donegal or within the Dún Laoghaire catchment area, which spans a large proportion of south county Dublin. We are also asking that an unaffected sibling of each MS patient volunteer a sample of blood for comparison to test for genetic susceptibility to MS."

The project aims to prospectively study people with MS in remission, relapse and progressive phases of the disease. Pro- and anti-inflammatory markers, particularly regulatory T cells, will be measured in a blood sample. A sample will also be taken to test for genetic susceptibility.



## What will be expected of you?

Once you have contacted Dr Lonergan, an appointment will be arranged for you at the hospital closest to you and a questionnaire will be sent out for you to fill in. On the day of your appointment you will be met by one of the research team who will be conducting your exam. This will take

approximately 30 minutes to complete. In the exam four things will be required of you:

1. General information about your MS
2. A blood sample
3. Neurological exam ie reflexes, co-ordination etc
4. Completed questionnaire.

Another sample will be taken for vitamin D levels and for markers of bone metabolism. Vitamin D stimulates the absorption of calcium and phosphate and is an essential link in bone resorption and formation and calcium metabolism, explains Dr Lonergan.

"Past sun exposure and vitamin D supplementation have been associated with decreased risk of MS. Studies suggest a role for vitamin D metabolism as a potential explanation of the increased risk of MS as a factor of distance from the equator. These findings may justify vitamin D supplementation trials in MS."

Researchers also plan to use this project to help perform a needs assessment for people with MS in Ireland

by means of a series of questionnaires. This part of the study will look at the quality of life implications for someone living with MS.

Dr Lonergan assures that no personal or family information given by volunteers to the study will be made public.

"It is hoped that this project will enable us to demonstrate the overall increasing incidence and prevalence of MS in Ireland by studying these three geographical areas," says Dr Lonergan.

If you have MS and are interested in becoming involved in the project, contact Dr Roisin Lonergan, Neurology Research Registrar, at 01 2214821 between 9am and 5pm, Monday to Friday, or email [msstudy@st-vincent.ie](mailto:msstudy@st-vincent.ie).

# NEW CARING GUIDEBOOK WARMLY RECEIVED

A NEW HANDBOOK offering advice to carers is proving a huge success across the country. In April, the Irish Red Cross launched the *Helping You To Care Handbook*, an illustrated guide to assist carers to provide the best quality of care. Since then, the feedback has been extremely positive, particularly from males.

With up to 150,000 people now caring for ill, elderly or disabled relatives in their own home, often under unexpected circumstances, the handbook sets out, in a step-by-step way, how best to carry out daily activities such as communication, personal hygiene, nutrition and mobility.

David Andrews, Chairman of the Irish Red Cross, says that in producing the guide the organisation took into consideration the fact that carers don't have time to sit down and read through a large book.

"The *Helping You To Care Handbook* is divided into easy-to-find chapters covering the essential issues. It includes comprehensive advice on all aspects of caring and will be useful to everybody, in particular parents, family carers and those working in the caring profession," he explains.

The handbook has received great reviews from both professionals and home carers. It has valuable and unique advice from professionals working in healthcare, public health, caring, finance and law.

Lydia O'Halloran, Community Services and Development Officer at the Irish Red Cross, says: "We have received very good feedback, from men in particular. Men mightn't be as quick to ring people and ask lots of questions, so this book means they have the information at their fingertips. We've also had great



**Health Minister Mary Harney joined twins Conor and Alyson Kelly-Byrne (9) with their grandmother, Annie Byrne, at the launch of the *Helping You to Care Handbook***

compliments about the amount of excellent information. People are saying we really haven't left anything out and that it's practical and easy to follow."

Topics covered in the book include personal care skills, infectious diseases, healthy eating and drinking, and maintaining and improving mobility. There is also information on leaving hospital, adapting the home and how to deal with hospital outpatient treatments. The handbook also deals with the difficult issues of caring for someone as they reach the end of their life and offers advice on how to make a will. A glossary of medical conditions is featured at the end of the book.

The Irish Red Cross recommends this book to anyone who is in a caring role, or who has to care for themselves alone without constant assistance. Its easy-to-read format means that people can refer to it quickly for advice on any problems they may encounter.

"I would highly recommend the book particularly for family and carers of someone with MS. I firmly believe it would be very useful," says Lydia.

The *Helping You To Care Handbook* costs €14.99 (postage is free) and is available from the Irish Red Cross at local 1850 650 651, from Monday to Friday 9am-5pm. Eason and bookshops nationwide are also distributing the book.

A EUROPEAN NEWS conference has highlighted the lack of neurological services in Ireland. In June, the European Multiple Sclerosis Platform (EMSP) spoke about this country's lack of services in comparison to our European neighbours, placing much media attention on Ireland.

According to the EMSP's Atlas of MS, an online database of MS services across Europe, Ireland is ranked bottom of the table when it comes to the ratio of people with MS to the number of neurologists.

Over 200 policy setters from across Europe attended the conference, where EMSP discussed European-wide policy and the recently developed Code of Good Practice on the Rights and Quality of Life of People Affected by Multiple Sclerosis.

The code aims to address major inequities in accessing services across Europe. It is hoped that individual countries will follow the code, allowing for

improved standards in four key areas critical for persons with MS:

- Equal rights and access to therapies and services
- A shared agenda in MS research throughout Europe



- Employment and job retention
- Participation and empowerment.

The code will be enhanced by a new project just launched by EMSP in conjunction with the European Commission: Multiple Sclerosis Information Dividend (MS-ID). The aim of the project is to establish an EU-wide MS register quantifying the number of people with MS in Europe and qualifying their experiences of MS in a range of categories.

MS Ireland will be working with EMSP on both projects, and is keenly aware of the need for accurate information on MS as a

condition and the appropriate services to address needs. The code of good practice will guide service development, while the MS-ID project will enhance clinical data on the number and experiences of people with MS in Ireland.

To learn more about the code and the MS-ID, log on to [www.ms-in-europe.org](http://www.ms-in-europe.org).

## MSIF UN convention campaign gains support

A CAMPAIGN TO get the UN convention on the rights of people with disabilities ratified has been building momentum over the past number of months. The Multiple Sclerosis International Federation's (MSIF) campaign reached new heights when the 100th country signed in mid-July.

The purpose of the convention is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.

The convention has been open for signing since March 2007. When a government signs the convention it indicates general support for the principles expressed in it and signifies a



government's intention to become legally bound by it. Ireland signed the convention earlier in the year. However, governments can sign the convention without being required to take any domestic action. Jamaica is the only country in the world that has ratified the convention. When 20

countries ratify the convention it will become legally binding and signatories must conform to its principles under international law.

To learn more about the convention, log on to [www.un.org/disabilities/convention/conventionfull](http://www.un.org/disabilities/convention/conventionfull).

# FUNDING BOOST TO TESCO CHARITY OF THE YEAR CAMPAIGN



**The nationwide physical exercise and activity programme 'Getting The Balance Right', has been awarded assistance from the Dormant Accounts Fund**

**MS IRELAND WAS** delighted to learn of its successful application to the Dormant Accounts Fund, which matches the money generated by the Tesco Charity of the Year campaign. Some €860,098 was awarded to assist with the running costs for the programme, which is due to start at the end of the year.

Anne Winslow, Chief Executive of MS Ireland, says: "With the additional funding we will now be able to offer programmes to more people in more locations over a longer period of time. This will have a tremendous impact on the physical health and mobility of many people with MS. The

extra funding will also enable us to do more comprehensive research, which will be carried out by University of Limerick Physiotherapy and Research Department."

Dormant accounts are accounts in financial institutions that have not been used, or insurance policies that have not been reclaimed by their owners for at least 15 years. Money from the accounts is being put into a fund and being given to organisations to assist in the personal, educational and social development of disadvantaged people or those with a disability. An allocation of €30m has been approved for the Dormant Accounts Fund

in 2007. MS Ireland is one of a number of successful organisations to receive funding so far this year.

'Getting the Balance Right' is a national physical activity, exercise and health promotion programme for people with MS. This project will operate over a two-year period and will offer a variety of opportunities to people with MS to maintain and improve the full range of motion that may have been impacted upon as a result of the MS disease process.

Full details of the programme will be available in the next issue of *MSnews*.

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