



MDI News Update



Two monthly newsletter – March/April 2006, Issue 28

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Editorial

Hello again,

Welcome to this issue of our newsletter. Since the last issue, MDI have had our 5th National Awareness Campaign, which went very well. Thanks to everyone who took part and sold chocolates. The money is still rolling in – we will let you know the total raised when all is in. Again, thanks to all.

Karen's "Research News" on page 2 looks at developments in FSH MD. Here you will also find details of a new CMT UK website.

Following recent requests from members, the entitlements section on pages 3 & 4 provides information about toll charges and telephone directory services for people with disabilities.

The MDI AGM will take on Saturday 6th May 2006 at 3pm in the Ashling Hotel, Park Gate Street, Dublin 7 (see page 5).



MDI National Awareness Day 2006 – Sligo
Fintan Flannery (MDI Family Support Worker) and Phil McGarry (Friend of MDI) selling chocolates at Sligo Shopping Centre for MDI. See page 6 for more.



Ronan & Marcella Gavigan, present Joe Mooney with proceeds from fundraising dance – see page 7 for more

With "Regional News" on pages 6 & 7 and also details of an Information Technology Course and the Ladies Mini Marathon, we hope there is something to interest everyone.

The next issue of this newsletter will be printed in June, so I would welcome any suggestions or articles etc. before then.

Enjoy the Easter break and until next time, take care.

Hubert McCormack
Editor



Research News

FSH Developments

The March-April 2006 edition of Quest, the American Muscular Dystrophy Association's magazine, brought attention to a development in research into facioscapulohumeral muscular dystrophy (FSH).

In 2002, scientists in America discovered a mutation that removes a section of DNA in an area called D4Z4 on chromosome 4, causing suppression of other genes in the area, which leads to FSH. However, the specific consequences of this mutation have now been identified.

Scientists from the University of Massachusetts, and from Milan and Pavia in Italy, have discovered that a gene known as FRG1 is a major suspect in causing FSH. Looking at genetically altered mice who produced more of the FRG1 protein, it was found that the higher the levels of the protein, the worse the muscular dystrophy symptoms, including muscle wasting, curvature of the spine and reduced exercise tolerance. Looking under the microscope, the muscles appeared dystrophic.

It was then found that high levels of FRG1 affected at least 2 other proteins, TNNT3 which normally regulates the muscles' ability to contract, and MTMR1, which can regulate muscle atrophy. It is thought that the effects could reach many other genes as well.

Davide Gabellini, one of the researchers from the University of Massachusetts, says that although many genes may be affected, suppressing or blocking FRG1

itself, may be all that is needed to remedy the effects of FSH. The new FRG1 mouse model will now be very useful in testing potential therapies for FSH.

For more information, check the American Muscular Dystrophy Association's website at www.mdausa.org

Karen Pickering
Information Officer

CMT UK Launches New Website



CMT UK, the UK organisation for people with Charcot-Marie-Tooth Disease, has launched its new website. MDI members with the

condition may be interested in the leaflets that can be viewed online, including "What is CMT" and "Managing CMT", which includes information about foot care, orthoses and pain management. There is also a members' section which requires registration, and here you can find a discussion forum, personal stories and news.

Although CMT UK is based in Britain, they welcome members from other countries. You can view their website at www.cmt.org.uk

If you do not have internet access but would be interested in receiving a hard copy of the "Managing CMT" document, please let me know by emailing karen@mdi.ie or phoning the Dublin office on 01 8721501 and I will forward it on to you.

Karen Pickering
Information Officer



Entitlements

Following recent requests from members, the entitlements section in this issue provides information about toll charges and telephone directory services for people with disabilities.

Exemption from toll charges for disabled drivers and disabled passengers in Ireland

Information

Disabled drivers and disabled passengers with specially adapted vehicles in Ireland are exempt from toll charges on national roads throughout Ireland.

Toll charges are currently in operation on the following four national roads in Ireland:

- East-Link Toll Bridge (Dublin)
- West-Link Toll Bridge (Dublin)
- North-Link M1 Toll (Drogheda By-Pass)
- M4 Toll (Kinnefad-Enfield-Kilcock)

Rules

You will need to complete an application form for exemption from toll charges on the East-Link, West-Link and M1 Toll. (If you are a disabled driver, driving an adapted vehicle you are exempt from tolls on the M4 Toll). Up to now Disabled Drivers were allowed to cross the East link Toll Bridge and the M1 Toll free on display of an International Disabled Person' Parking Card. However, now a special card called a Concessionary Travel Card must be produced when going through all tolls. You will be issued

with a Concessionary Travel Card when you apply. When you get your card it may state "West Link Toll Bridge" on it. Even so, this is the card you use for free passage through the East-Link, West-Link and M1 Toll. If you do not have your Concessionary Travel Card with you, you must pay the normal toll at the barrier. (You just need to show you are a disabled driver driving an adapted vehicle for free passage through the M4 Toll).

The Disabled Person's Parking Card and the Concessionary Travel Card are not interchangeable. In other words, you must have a Concessionary Travel Card to be exempt from paying a toll.

Rates

Provided you have a Concessionary Travel Card for use on the toll bridges, you do not have to pay tolls. If you do not have a Concessionary Travel Card, you must pay the normal tolls on all Bridges. The normal tolls on all four tolls roads in Ireland from 1 January - 31 December 2006 are as follows:

Vehicle	East Link	West Link	M1 Toll	M4 Toll
Car	€1.45	€2.00	€1.60	€2.50
Motorcycle	Free	€0.80	€0.90	€1.30
Van/Bus	€2.10	€3.10	€2.90	€3.80

How to apply

To avail of the exemption from toll fees at the East-Link, West-Link and M1 toll bridges, you should complete an application form for the Concessionary Travel Card.

Your Concessionary Travel Card lasts for three years from the date it is issued. If you change your car during this period, you must return your card to National Toll Roads and a new card will be issued.



Your card must also be returned after three years when it expires and a new card will then be issued to you. Each time you pass through the toll plaza, you must show your card to the toll operator and you will be allowed pass through for free. Failure to show your card will mean you must pay the appropriate toll.

You simply need to show you are a disabled driver, driving an adapted vehicle to qualify for free passage through the M4 Toll (see editors note below).

Where to apply

For an application form for a Concessionary Travel Card contact:

National Toll Roads PLC
Concessionary Travel Section
East-Link Toll Bridge Ltd.
York Road
Ringsend
Dublin 4
Tel: (01) 668 2888
Fax: (01) 668 2562
E-mail: info@ntr.ie

This document was printed from the Oasis website
(<http://www.oasis.gov.ie/>).

Editors Note:

The M4 Toll Plaza is operated by a company called Eurolink (all other tolls are operated by Westlink). MDI have written to Eurolink querying their decision to exclude disabled passengers from free passage on the M4 as we believe it is not consistent with existing exemptions from toll charges on national roads throughout Ireland. We also believe that a uniform approach needs to be implemented to avoid discrimination and ensure equal treatment for all disabled motorists, regardless of the extent of their disability. We will keep you posted.

Free Directory Enquiry Service for People with Disabilities



Did you know that Eircom provide a Free Directory Enquiry Service for People with Disabilities?

If you would like to avail of this service call freephone 1800 574574 and ask for an application form for the free directory enquiry service for disabled persons. When you have completed this form, it must be signed by your G.P. and returned. Eircom will then issue you with a Personal Identification Number (PIN). Anytime you have a directory enquiry you dial 10, ask for "special enquiries" and quote your PIN Number. Eircom will then provide you with the information you are looking for free of Charge.

Caroline Moran
Family Support Worker



UK Motoring Atlas Launched for Travellers with Disabilities

A new guide has been developed for people with disabilities, containing information to make your journey in the UK smoother. This includes information about what petrol stations are accessible, where you can park and how accessible the accommodation is. It has been developed by Gowrings Mobility, the UK's market leader in accessible transport.

Gowrings says that the guide is “a unique road atlas covering all of the UK, incorporating useful information for disabled people such as parking for Blue Badge holders; accessible car parks and petrol stations; tourist information; locations of Shopmobility and mobility stores; accessible beaches; parking regulations council by council; accessible toilets and accommodation.”



The 190 page road atlas is split into two sections: a national road atlas and a more detailed street mapping of 65 city centres.

The guide is now available from Gowrings Mobility for

£12.00 sterling (approximately €17.50). Visit their website at www.gowringsmobility.co.uk for more information.

MDI AGM

Saturday 6th May 2006

The Annual General Meeting of Muscular Dystrophy Ireland will take on Saturday 6th of May 2006 @ 3pm in the Ashling Hotel, Park Gate Street, Dublin 7.

In advance of the AGM Prof. Kate Bushby will make a presentation on the UK based, Exon Skipping research. The presentation will start at 12 noon and will be followed by lunch. The following is a short biography of Kate Bushby.

Prof. Kate Bushby is a member of the consortium in the UK which is researching exon skipping as a potential therapy for Duchenne muscular dystrophy, and has agreed to attend the MDI AGM and talk to members about this research. Prof. Bushby is a clinician and researcher based in the University of Newcastle, and is known to some members from her work in the Newcastle Muscle Centre. The research has progressed rapidly since Dr. Ian Graham spoke at the last AGM in October, with safety clinical trials scheduled to begin this year. Prof. Bushby will talk about these advances and the future aims of this research.

More details will be sent out to members in due course.



Regional News

North-West Region

"First off the Blocks with the Chocs!! "

On behalf of MDI, I would like to sincerely thank "everyone" in Donegal, Sligo and Leitrim for their continuing support and contributions in promoting and highlighting the cause of Muscular Dystrophy in the North-West Region. I would also like to extend a special thank you to Ann Conlon (Sligo), Georgina Reddin (Sligo), Kevin Harrison (Leitrim), Margaret Harkin (Leitrim) and Marian Cunningham (Leitrim) for their time and effort with this years Awareness Day. Thanks again folks!!

Fintan Flannery
FSW North West Region

Eastern Region

MDI Dublin Branch Support Group Meeting



Coffee Morning

Monday 24th April 2006

Jury's Inn Hotel, Christchurch,
Dublin
from 10.00am to 12.00pm.

For more information contact:
Catherine on: 086 3834428 or
Eithne on: 086 3830966

All Welcome



Pictured selling chocolates for MDI in Sligo Shopping Centre are Friends of MDI, Anne Conlon (left) & Phil McGarry for Awareness Day 2006.



Western Region

Fundraising Dance Raises €20,000

A Fundraising Dance took place on Friday 22nd March 2006 at the Kilbride Community & Leisure Centre in Roscommon, the proceeds of which were for MDI.

Organised by MDI member Marcella Gavigan and her friends, the night was a huge success and raised €20,000 which will go towards MDI's Summer Camps and Research into muscular dystrophy.

MDI would like to thank Marcella and her organising committee for all their hard work in making this event such a huge success. Congratulations and well done!

North East Region

€3,000 for a Swim

On Sunday 4th March, MDI was presented with a cheque for €3,000 by the Carrickmacross GAA club.

The GAA Club along with many locals raised this money through their annual Christmas Swim on Christmas Day, which this year celebrated its 25th anniversary. Over 70 participants took part and not unlike any other year the crack was mighty!

MDI was just one of four beneficiaries of this years fundraising event. It goes to prove that they're all a very hardy lot in the North East. Thanks to all concerned.

Brenda Hopkins
MDI Youth Worker - North East



Pictured being presented with some of the proceeds raised from a fundraising dance in Roscommon are (from left to right): Marcella Gavigan, her son Ronan and MDI Family Support Worker, Caroline Moran.



Neurologist Position Approved for Sligo

The HSE has sanctioned funding for a consultant Neurologist at Sligo General Hospital. The approval paves the way for the HSE to start the recruitment process shortly. Welcoming the news Sligo / Leitrim Deputy Jimmy Devins, believes that the move is a major boost to the health service throughout the North West region.

This appointment will be of tremendous benefit to people from throughout the North West. It means that those with Neurological conditions such as Muscular Dystrophy (MD) Multiple Sclerosis (MS) Strokes etc, will be able to access consultant care at Sligo General Hospital and will now not have to travel to Galway or Dublin as is the case at present.

“This welcome news is the end result of a concerted campaign over the past number of years to get a consultant neurologist post sanctioned at Sligo General Hospital.

As vice chairman of the all-party Oireachtas committee of Health and Children I have been actively campaigning to have the number of neurologists increased in Ireland.

Following a recent presentation on the Neurological Services it has been very apparent that certain areas of the country including the North West were deficient in Neurological cover”. Said Deputy Devins.

This appointment will also increase the level of expertise and services available at Sligo General Hospital, which is building on its regional importance. *“In addition to this very welcome news I am delighted that the HSE have also announced that there will be a tele-physiological link up between Sligo General Hospital and the Beaumont Hospital in Dublin, which will start in April. “This will mean that patients can have their EEG’s performed in Sligo General Hospital and have their results immediately read and commented upon by a consultant in the Beaumont and the result reported back to Sligo immediately. This is a wonderful and very welcome example of modern telecommunications being used for the benefit of patients in the North West region”.* Deputy Devins added.

MDI welcomes these developments and will monitor its progress in the North West and the rest of the country.



Dating4Disabled.com was developed by a group of volunteers who wanted to provide more social, intellectual and romantic outlets for disabled individuals. Dating4Disabled.com has members from over 15 countries world-wide. It is a place for people of all nationalities, backgrounds and disabilities to share, connect and just be heard.

The Dating4Disabled environment is welcoming and user-friendly. Advanced internet tools make for easy communication, and facilitate a convenient and fun way to create connections within the disabled community.

The members of Dating4Disabled can network internationally in an understanding, safe and non-committal atmosphere.

This unique cyberspace community facilitates an embarrassment-free opportunity for disabled individuals to express themselves, make friends, and hopefully find a partner for life, with out the pressure of uncertain face-to-face meetings.

Membership is free, simple and quick. In the 2 minute sign-up, people create a profile which tailors their online preferences and enables other members to know more about them and what they are looking for.

The website address for Dating4Disabled is www.dating4disabled.com . Here you can see all the features without becoming a member. Just click on the orange feature buttons on the left hand side of your screen.

For more information or any questions email Erin Shamberg at: erin@dating4disabled.com



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I.T. By Distance Learning

If you live in West / South West and central Dublin, you may be interested in taking part in a home supported Information Technology by Distance Learning programme.

The National Learning Network in Tallaght is running this course, designed specifically for people with disabilities who are unable to access existing centre-based training courses. They will also provide all the necessary computer hardware and software needed by participants.



No previous computer skills are required, and training will be provided to European Computer Driving License (ECDL) certification level. There will also be a job seeking skills section on the programme, to assist you to access employment once trained.

The course will last for one year, and is completed at home with some home support visits from a tutor and monthly group meetings.

Participation will not interfere with a person's current allowances or benefits and it is not means tested. The only condition for participation is that applicants register with FÁS.

If you would like to apply for this course and live in West / South West or central Dublin, please contact:

John Doolin, Area Manager
or Anne Marie MacMahon, Programme Instructor,
National Learning Network Tallaght,
Unit 77, Broomhill Rd,
Tallaght, Dublin 24
Tel: 01 4525777
Email: tallaght@nlm.ie

Alternatively, I have some application forms in the Dublin office and can forward them on to you. Contact me by telephone 01 8721501 or email karen@mdi.ie

MDI Conference Report October 2005

If you are receiving this newsletter by post, you will have also received a copy of MDI's Research Conference Report which took place in October 2005. This conference featured four high profile speakers, namely: Joseph Irwin, Honorary Director of Research with the Jennifer Trust for Spinal Muscular Atrophy, Dr. Ian Graham from the Royal Holloway, University of London, Professor Kay Ohlendieck, NUI Maynooth and Michael McGrath, Executive Director and co-founder of the Muscle Help Foundation in the UK.

If you only receive this newsletter by email, and would like a copy of this report sent to you, contact Karen Pickering, Information Officer on (01) 8721501 or email karen@mdi.ie



Flora Womens Mini Marathon

Be part of the MDI Team



Bank Holiday Monday

5th June 2006

Application forms are now available to register for this year's Women's Mini Marathon in the Evening Herald each Thursday and Saturday or you can register online at

www.womensminimarathon.ie

Why not run for MDI

We will be meeting in Café en Seine on Dawson Street after the event. For further information, sponsorship cards and T-Shirts, contact Steven at: 1800 245300
or E-mail steven@mdi.ie

Your support would be much appreciated