



# MDI News Update



Two monthly newsletter - Issue five, May 2002

Muscular Dystrophy Ireland Coleraine House, Coleraine St, Dublin 7.  
Ph: 01 8721501 / 872 3826 Email: [info@mdi.ie](mailto:info@mdi.ie) Website: [www.mdi.ie](http://www.mdi.ie)

## Editorial

Hello again,

Since the last issue of the newsletter MDI have been busy getting ready for the summer activities, which kicked off with the first of our holiday breaks, when a group of 15 adult members spent five days in Kilcuan Holiday Centre, Clarenbridge, Co. Galway from 13<sup>th</sup> - 17<sup>th</sup> May. Further holidays are planned in Roscommon from 1<sup>st</sup> to 7<sup>th</sup> July for our younger members and in Galway from 27<sup>th</sup> July to 3<sup>rd</sup> August for teenage members. A youth exchange with our Spanish counterparts is also taking place in September. Details of all of the above will be furnished in due course.

The Ladies Mini Marathon is taking place on Monday 3<sup>rd</sup> June and MDI have over 100 runners participating. Remember, all runners are invited back to the Mansion House on Dawson Street afterwards for a post marathon reception where refreshments will be served and you will have an opportunity to meet fellow runners and members.

In this issue, among other things, is a very interesting article on stem cell research by Karen Jameison, Information Officer with MDI. Stem cell research is currently one of the biggest areas in research and it is thought that this therapy could be used for all types of muscular dystrophy, however at the moment it has only been tested on the Duchenne model. To date, scientists have been working with mice but they want to try it on other animals before beginning human trials. See page 2 for more.

Included also are details of a new Physical & Sensory Disability Database which the Health Boards are compiling over the next couple of months for the purpose of improving the planning and provision of services for people with disabilities. Many of you may have received details on this. For more details on this see page 3.

You will notice that there are fewer pages in this issue, as we received no articles from members/branches. Remember this is your newsletter, why not send in any articles, photographs etc., or share your experiences with fellow members, which I'm sure would be of interest.

We hope you enjoy this issue. Until next time.

Slán,

**Hubert McCormack**  
**Editor**



With World Cup fever in the air, and the recent testimonial match for Niall Quinn, I thought this photograph, which was sent in to us by Eamon Nolan from Newbridge, was very appropriate for the front cover.

Pictured with Niall Quinn are MDI member's Colin Boland from Ashford, Andrew Nolan from Newbridge and Steven Valentine from Greystones.

The photograph was taken at Andrew's 18th Birthday party last September, when Niall Quinn attended after the Holland match.



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## **Research Update: Stem Cells**

Since I started working in MDI, a number of members have asked me what is going on in research around the world. In the coming newsletters, there will be a series of articles on the status of research into muscular dystrophy, and I will be covering all the different types. This first article is a general introduction to stem cell research as this is one of the biggest areas at the minute.

### **Stem Cells vs. Myoblasts**

Some members may remember hearing about myoblast transfer a few years ago. Myoblasts are cells which make up muscles, and it was thought that transferring myoblasts from a healthy person into a person with muscular dystrophy would regenerate their muscles. However, although it seemed to work in mice, results in people were very disappointing. Stem cells are different, in that they are almost blank slates - they have the potential to become any type of cell, from muscle to skin to blood and so on. Everyone has stem cells, and scientists can isolate them from any other cell in the body.

### **How are Stem Cells Used?**

The idea is to use stem cells to stop the muscle weakening seen in muscular dystrophy and make the weakened muscles better. There are two ways to do this. Firstly, a sample of muscle would be removed from a healthy person. The stem cells would be isolated and grown in the lab, and then injected into the muscles of a person with muscular dystrophy. The problem with this could be that the stem cell transfer would be rejected by the immune system, although this still has to be tested.



Another method would be to take a sample of muscle from a person who has muscular dystrophy. The stem cells would be removed and grown in the lab. To make sure that these cells won't carry the genetic fault that led to the condition in the first place, they are treated with a corrective gene. A virus has to

be used in order to trick the cell into accepting the corrected gene - if it thought that the gene was foreign, then it would reject it and the transfer wouldn't work. This is like when a cuckoo takes its place in another bird's nest, and tricks the mother bird into believing that it is one of its family. The virus will cause no problem to the person, as it is made in the lab with the harmful parts removed. The treated stem cells are then injected back into the person's muscles. So far, this method has been slightly less successful than the first, but the research is continuing.

### **Benefits of Using Stem Cells**

It is believed that stem cell transfer would be more successful than myoblast transfer because while myoblasts die after they are used, stem cells keep regenerating and so they could keep making muscle long after the transplant. Stem cell research has also shown so far, that the treatment produces new blood vessels and nerves as well as muscle fibres. There are also ways to prevent the person's body from rejecting the treatment, such as using the virus.

### **Work for the Future**

While stem cell research is very exciting, there is still some way to go. Scientists have been working with mice but they want to try it on other animals before beginning human trials. Also, although there was muscle regeneration in the mice, in some of them it was not enough to be of practical benefit, so the procedure needs some work. Although it is thought that this therapy could be used for all types of muscular dystrophy, at the minute it has only been tested on the Duchenne model. Despite these problems, the future is looking bright for stem cell research.

In the next newsletter, I will give an update on further research into Duchenne MD. For more information on stem cells, the use of viruses, or any other research area, please contact me in the Dublin office.

**Karen Jameison  
Information Officer, MDI**



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## ***Physical & Sensory Disability Database***

Over the next couple of months the various Health Boards throughout Ireland are gathering information to develop a new Physical & Sensory Disability Database for the purpose of improving the planning and provision of services for people with physical and sensory needs that are disabling. Similar types of database in other areas have proved successful in getting more funding for services. They have also improved the way in which the services are planned and provided.

If you haven't been contacted already, MDI will be contacting you over the coming months inviting you to have your name and details included in this database. Your name will not be included without your consent.

MDI believe that by participating in this database, it will provide our members with access to greater funding and services. We also feel it is important that as many of our members as possible register, so that the needs of those with muscular dystrophy are fully catered for.

The future design and delivery of services will be based on the information in the database. This will include the provision of services such as regional basis occupational therapists, physiotherapists, PHN's, speech & language therapists, aids & appliances, respite, counselling, genetic counselling, vocational training, etc.

We believe that the particular needs of those with muscular dystrophy will be taken into account only if the Health Boards are aware of how many people need these services.

The Health Boards have guaranteed that the information gathered will not in any way effect social welfare benefits/health board payments or entitlements.

We would therefore recommend all our members to register when you receive the letter giving details of this database. As mentioned, if you have already received such a letter, we would encourage you to register. If you have any questions, contact Joe Mooney, at the MDI Office.

## ***Congratulations***



Many of you will remember Marta Garcia pictured above, with her husband Javier and their new born baby boy Pablo. Marta worked with MDI as Youth / Respite Worker for two years. Congratulations on the new arrival. Marta was instrumental in helping us organise our Spanish Exchange, which takes place in September.



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## ???? DID YOU KNOW ????

### Companion Free Travel Pass



This pass allows the individual to travel free (alone or accompanied) on busses and trains. Travel times are unrestricted as long as your he/she remains in full-time education.

**Apply to:** Free Schemes, Department of Social, Community and Family Affairs, College Road, Sligo.

### Disabled Person's Parking Card



This pass may be used in any vehicle in which the individual travels. It allows the vehicle to be parked at parking meters for an unspecified length of time at no cost and spaces specifically designated for people with disabilities.

**Apply to:** The Disabled Drivers Association, Ballindine, Co. Mayo. Tel: 094 64266.

### Incapacitated Child Allowance / Tax Free Allowance

There is a tax-free allowance of €1,015 available to the parents of a child who has a permanent physical or sensory disability. Your income level does not affect the entitlement to claim the allowance.

**Apply to:** Inspector of taxes, Office of the Revenue Commissioners.

### Attention any golfers



MDI are seeking members and friends who may be golf fanatics, poor golfers or fun golfers to approach their local clubs to perhaps run a golf classic to support the work of MDI.

If you know of any golf clubs that can help and you need support in organising such an event, contact our Information Officer, Karen Jameison at 1800 245 300

### Next Newsletter

We are now looking for articles, branch news, photographs, details on up-coming fundraising / social events etc. to be included in this issue.

Article, photographs etc. should be sent to Hubert McCormack at the MDI office, Coleraine Street, Dublin and must reach us **before Friday 12<sup>th</sup> July 2002**. Articles received after this date will not be included in the next issue.



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## Arts and Disability Awards Ireland 2002

If you are a disabled artist living in Ireland, working in all art forms, you are eligible to apply for a grant which may be worth up to £5000 sterling.

There are two deadlines for application; round one on 24<sup>th</sup> May 2002 and round 2 on 6<sup>th</sup> December 2002.

The Arts and Disability Awards Ireland are a partnership between the Arts Council of Northern Ireland and Arts Council / An Chomhairle Ealaion and administered by the Arts and Disability Forum.

Any interested artists should contact the Arts and Disability Forum for an information pack at Unit 45, 30-50 Distillery Street, Belfast, BT12 5BJ; telephone: 048 90 239450; fax: 048 90 247770; email: adf.dforum@dnet.co.uk

### For Sale



Nissan Cargo Van (1998) 16,000 miles.  
Adapted with electronic lift fitted.  
Regularly serviced and in perfect condition.  
For further details phone 0505 46279

## Awareness Day

Thanks to all our members and friends of who sold, and/or distributed chocolates for our recent awareness day. If you haven't returned the proceeds, please do as soon as possible. If you have, thank you.

There are some cartons of chocolates left over, so if any of our members are organising any functions or fundraising events, perhaps you could sell some. As these chocolates are perishable, we would appreciate your support in helping to sell them before their sell by date. Thank you.

## Fundraising

### Cabaret / Fundraising Night

A Cabaret / Fundraising Night will be held on Sunday 2<sup>nd</sup> June 2002 at "Cullens on the Hill" Pub, Hacketstown the proceeds of which will go to Muscular Dystrophy Ireland. Music by: "The Pub Crawlers". Doors open at 8.00pm. Admission €5.00

### Church Gate Collections

Church Gate Collections will take place in Donegal on 25<sup>th</sup> & 26<sup>th</sup> May 2002, the proceeds of which will go to The Donegal Branch of Muscular Dystrophy Ireland.

### Flag Days

The Dundalk Branch of Muscular Dystrophy Ireland are holding their annual flag day on Saturday 22<sup>nd</sup> June 2002.

The Cork Branch of Muscular Dystrophy Ireland are holding their annual flag day on Saturday 11<sup>th</sup> July 2002.

All branches would appreciate any support you can give. Thank you.



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Membership subscriptions for 2002 are now overdue. If you haven't already paid your subscription this year please complete this form and return to the address below. If you have paid your membership for this year, thank you.

## Muscular Dystrophy Ireland - Membership Application Form

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

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

Telephone: (Home) \_\_\_\_\_ (Work) \_\_\_\_\_

Email: \_\_\_\_\_

Date: \_\_\_\_\_

Please tick whichever of the following applies to you:  
Person with MD  Family Membership   
Friend of MDI

<i>Annual Subscription Rates</i>	
Person with MD	€13.00
Family Membership	€19.00
Friend of MDI	€13.00

If you would like to make a donation additional to the membership fee, please indicate the amount here € \_\_\_\_\_

To enable us to update our records we would appreciate it if you would provide the following information regarding your family if applicable:

Name(s) of Person(s) with MD	Date(s) of Birth	Type of MD
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

All cheques and postal orders should be made payable to Muscular Dystrophy Ireland. It is also possible to pay your subscription by Bank Giro to our account; Muscular Dystrophy Ireland Savings Account at Bank of Ireland, 2 College Green, Dublin 2. Branch Code 90-00-17 A/C No: 75261619

Please complete this form and return it, with the relevant membership fee (see above) to: Muscular Dystrophy Ireland, Carmichael Centre, Coleraine House, Coleraine St., Dublin 7