



# MDI News Update



Two monthly newsletter – Jan/Feb 2006, Issue 27

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## Editorial

Hello again,

Welcome to the first issue of our newsletter this year - a little late, but better late than never eh?!!!!

Valentines Day is almost here and once again this means chocolates, chocolates, chocolates!!! This year, SPAR have come on board and will be selling our chocolates in all their stores nationwide, which is a great boost to our campaign. Also, with Roches Stores once again on board and the support of our members, hopefully we can make this year an even bigger success than previous years.

Pictures say it all in this issue, with lots of photographs of recent events! With information on entitlements and details of previous and upcoming branch news etc., I hope there is something to interest everyone.

Until next time, enjoy!

**Hubert McCormack**  
Editor



### Photo Details

**Top:**

Des Redmond, Marketing Manager Spar Ireland and Joe Mooney, Director MDI pictured at a photo-shoot to launch MDI's Awareness Campaign 2006.

**Left:**

Tony Tynan, (Rotary Club of Dublin Viking) presents Florence Dougall (Chairperson MDI) with a cheque for €2,200 in the presence of An Tánaiste Mary Harney T.D. at the official opening of the MDI Office on 13/01/06



## Research News

### Exon Skipping as a Potential Therapy for Duchenne Muscular Dystrophy Consortium Research Advances

As has been reported previously in the newsletter, a group of scientists in the UK have formed a consortium and are working with other groups in the Netherlands and Australia to develop exon skipping as a potential therapy for Duchenne muscular dystrophy.

An exon is a piece of DNA that contains instructions for making a protein. In Duchenne muscular dystrophy, there is some form of a mutation in an exon that disrupts the code for making the protein dystrophin, and this leads to muscle weakness. The idea of exon skipping is to make a piece of genetic material called a molecular patch, which would act like a bridge connecting exons on either side of a damaged exon, skipping the damaged part. This would then enable some dystrophin to be made and Duchenne muscular dystrophy would come to resemble the milder form of the condition, called Becker muscular dystrophy.

Exon skipping has been tested in mice and was found to be highly effective, with a single treatment resulting in dystrophin appearing in half of all muscle fibre cells. The consortium is now preparing to begin clinical trials. They will begin two trials, one using intramuscular injections and the other will be a systemic (intravenous) trial. The intramuscular trial should be completed by winter 2006 and the intravenous trial should be completed by the end of 2007. These are trials to determine how safe and effective the technique is, and participants will not have a therapeutic benefit.

The UK Department of Health provided £1.6 million and this will fund the research until the end of 2007. However, in order to complete the research, further funding is required. There must be further toxicology testing and the aim is to run a chronic administration study in 12 children between January 2008 to March 2009.

This is not a cure and will not be suitable for every child with Duchenne muscular dystrophy. However, it would make an enormous difference to the quality of life for many boys and is the most promising hope of an effective treatment at the moment.

*Karen Pickering  
Information Officer – MDI*

## MDI AGM

The 2006 Annual General Meeting of Muscular Dystrophy Ireland will take place on Saturday 6<sup>th</sup> May at 12pm in the Ashling Hotel, Park Gate Street, Dublin.

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



## Disability Related Entitlements

*In response to recent queries received by MDI, the following information has been compiled by MDI Family Support Worker Caroline Moran, which some members may find useful.*

### Domiciliary Care Allowance:

This is a health board payment to the parent or carer of a child with a disability. It is a monthly payment of €250.90 payable from birth up to age 16. It is means tested but only the child's means are taken into account. Recipients of D.C.A are entitled to an annual Respite Care Grant this is paid automatically in June. Application forms for D.C.A are available from your local Health Board.

Those in receipt of Domiciliary Care Allowance may also be eligible for Carer's Allowance or Carer's Benefit. Both of these payments however are subject to certain conditions.

### Disability Allowance:

This is a social welfare payment of €165.80 payable to a person with a disability who is aged between 16 and 66. It is means tested so your means and that of your partner are taken into account but your parents' means are not.

People in receipt of D.A can also qualify for Free Travel, a Free TV licence, Free Telephone Rental & Free Electricity Units. If you are living alone you should also qualify for a Living Alone Allowance.

Those in receipt of D.A can earn €120 per week without it affecting their D.A payment.

Application forms are available from your local Social Welfare Office.

A parent or guardian caring for a person who is in receipt of D.A may qualify for Carers Allowance this however is means tested.

*Caroline Moran  
Family Support Worker  
Western Region*

## MDI Summer Camps 2006

### Provisional dates

*Provisional* dates have been booked for 2006 Summer Camps as follows;

Kilcuan, Clarenbridge, Galway:  
Children: 08/04/06 - 13/04/06

Kilcuan, Clarenbridge, Galway:  
Adult Camp: 08/05/06 - 14/05/06

Share Village, Fermanagh:  
Children: 14/07/06 - 21/07/06

Kilcuan, Clarenbridge, Galway:  
Young Adults: 19/09/06 - 25/09/06

For more information: Contact:

Kate Power, Respite Co-ordinator  
Tel: 086 6066103



# MDI News Update



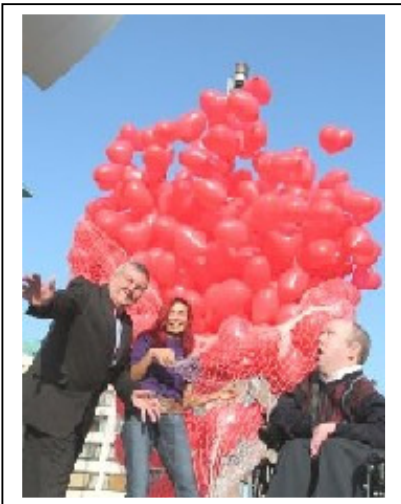
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## MDI National Awareness Day 2006

14<sup>th</sup> February 2006

# Photo Shoot

Have a Lily O'Brien's heart shaped chocolate and support MDI



**Photo Details** – MDI Awareness Day Launch, 31<sup>st</sup> January 2006  
*Top Left:* Hazel Kaneswaren, (Musician) and Joe Mooney  
*Top Right:* Joe Mooney, Hazel Kaneswaren, & Steven Valentine with Telly Tubby aka Pauric Cormican (Joe's PA!)  
*Above:* "Up, up and away" - Des Redmond, Marketing Manager, Spar; Hazel Kaneswaren and Joe Mooney release 500 heart shaped balloons to mark the launch of MDI's Awareness Campaign for 2006.



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The MDI office was officially opened by An Tánaiste Mary Harney T.D. on Friday 13<sup>th</sup> January 2006. Below are some photos which capture the days proceedings.



### Photo Details

Top left: An Tánaiste Mary Harney T.D. and MDI Chairperson Florence Dougall.

Top right: MDI Member Simon Jameson makes a presentation to An Tánaiste Mary Harney T.D.

Middle right: An Tánaiste unveils the plaque

Bottom left: An Tánaiste and MDI Chairperson address the gathering

Bottom right: MDI Members Ursula Hagerty (Dublin) and June Scannell (Cork)





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## Branch News

### Cork/Dublin Branch

#### Lapland Trip

14<sup>th</sup> December 2005

On the 14<sup>th</sup> December 2005 and after months of fundraising a group of us from the Cork and Dublin Branches of MDI headed off on a “dream-come-true” trip to Lapland. One plane left from Dublin and the other from Cork. Aboard the plane, we were treated to a sumptuous lunch and all the children also received colouring books. We landed in Lapland at 2.30pm local time and it was dark!! We were all given snow suits and when well wrapped, we headed for the snow slopes. The children got their first taste of the snow with tobogganing near the hotel for the evening. Despite several feet of snow everywhere and the temperature reaching minus 17 degrees, the fun we were having in the snow kept the cold at bay.

After tobogganing, we checked into warm, cosy and luxurious log cabins which even had a private sauna for us to enjoy!!!!

The next day we were up early to darkness!!! Day only reaches twilight at about 10.30am. We took the bus to Santa’s Winter Wonderland where we enjoyed such activities as tobogganing, snow

mobiling, reindeer sleigh rides, and the climax of it all.....we met Santa and his elf helpers in Santa’s log cabin. Everyone received a reindeer bell and Santa listened to all our Christmas wishes. We had our photos taken on his knee and left with a warm and happy heart. We then headed off to a husky farm where we enjoyed husky sleigh rides and got to hold a husky puppy.

On the next and final day of our trip, we were treated to a special Finnish Christmas lunch. Here we had a private meeting with Santa who once again with his helper elves, handed out presents to all the children. We then went to visit Santa’s Village where we crossed the Artic Circle and visited Santa’s Post Office.

We then headed back to the airport, saying a big goodbye to Snowdrop our Finnish Santa helper who was so special to us all.

On the plane home, we were all treated to a huge Christmas party, with Martin Laurence from Dublin winning the “Best Santa Letter” competition, and Joe Barry from Cork winning the “Best Decorated Seat” competition.

Everyone had the trip of a lifetime, it made all the hard fundraising really worthwhile.

Thanks for all the memories,

*Love Sinead and Glenn  
MDI Dublin Branch*





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## Galway Branch News

Hello Everyone

It's nice to be back writing for the Newsletter. In this edition I would like to tell you about the Christmas Party for the MDI Galway Branch. It was held in the Salthill Hotel on 15th December 2005. Caroline Moran (FSW) and Aisling Dermody (YRW) for the region came along, as well as many other members. MDI Director, Joe Mooney and his wife Ashling also travelled down from Dublin – in all, there was a great turnout.

Lovely finger food was served and everyone had the chance to mingle. Spirits were high and it didn't take long before we were all up on the dance floor enjoying ourselves. Of course Santa was the main attraction and he even had time to have a dance with some of the members.

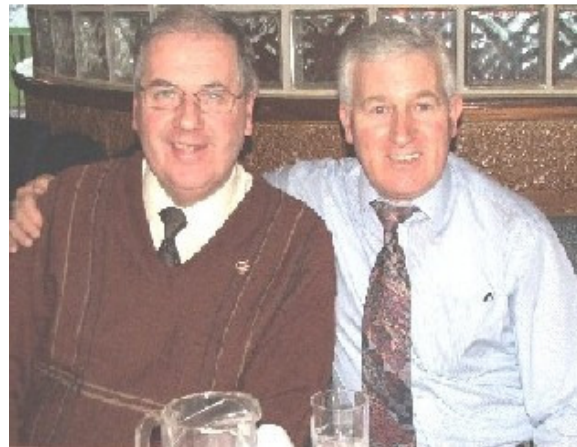
It certainly was a very good evening and we all enjoyed ourselves very much. The atmosphere was fantastic, dancing, singing, chatting, eating and drinking. It was great!

Until next time, from all at the Galway Branch, keep warm and stay healthy.

*Eileen Gormley  
MDI News - Galway*



Eileen Gormley admiring 1<sup>st</sup> prize (a "Gingerbread House") at the Christmas party raffle, which was won by Eamon Joyce from Galway



Pictured at the North East Branch Christmas party are MDI members Jerome Sheerin and Terry Dullaghan from Dundalk.

## MDI Midlands Branch

The MDI Midlands Youth/Drama Club recently completed a short film which they produced last year entitled: "The Brandy Hotel" which was shown at the 1<sup>st</sup> Annual Rush Film Festival in the Irish Film Institute on the 10<sup>th</sup> of December 2005. The aim of the film festival is to promote film and young people. The film was well received and got good reviews.

If you would like a copy of this DVD, it can be ordered for €15.00. For more information contact Sinead Glennon on: 086 8399285.

## Power Soccer Dates 06

Power soccer dates for 2006 are as follows:

### Munster Area

Date	Venue	Date	Venue
11/02/06	Limerick	04/03/06	Tralee
25/03/06	Limerick	22/04/06	Limerick

The Cork Branch are also organising a Boccia Tournament on 4<sup>th</sup> March. For More details on any of the above, contact Mary Rose Howell on: 086 6066104

### Dublin Area

Date	Venue	Date	Venue
17/02/06	DCU	25/03/06	DCU
29/04/06	DCU		

For More details contact Karen Leonard on: 086 6066109

## Fundraising Dance



A Fundraising Dance will take place on

Date: Friday 3<sup>rd</sup> March 2006

Venue: Kilbride Community & Leisure Centre,  
Co. Roscommon

Music by: La Bamba

Time: 10.00pm

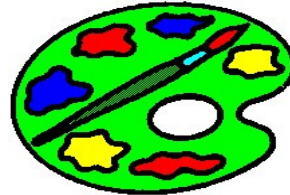
Tickets: €5.00

The proceeds from this dance will be presented to Muscular Dystrophy Ireland and all money raised will go towards funding research into muscular dystrophy.

Come along and bring your family and friends. A great night is expected and proceeds are for a very worthwhile cause.

For more details contact Marcella on: 086 8748367

## Access is for Everybody Poster Competition.



If you have a budding artist in your family, take a look at the poster competition *Access is for Everybody* on

[www.dublin.ie/aaweek](http://www.dublin.ie/aaweek). The competition hopes to create awareness among young people in relation to access in the city, promoting greater accessibility for all citizens regardless of disability, language or age. With fantastic prizes including Xbox and Play Station consoles and one hundred cinema tickets, entries are invited from two age groups: 14 years & under and 15-18 years. To download competition details log onto [www.dublin.ie/aaweek](http://www.dublin.ie/aaweek).

*Access is for Everybody* poster competition forms part of an accessibility awareness campaign launched by the Dublin City Development Board led by Dublin City Council. For further information contact Denise O'Grady on Tel: 2223729 or email [denise.ogrady@dublincity.ie](mailto:denise.ogrady@dublincity.ie).





## Photography Competition

In the last issue of the MDI Newsletter, I mentioned details of a photography competition which EURORDIS were organising for its members, of which MDI is one. Well, here are more details.

### Living with a rare disease in Europe

Grab your cameras and get ready! Eurordis has launched a photo contest for its members. The theme of the contest is “Living with a rare disease in Europe”. We are encouraging each of you to participate and submit up to five of your best pictures.

The contest is open from 1 January till 31 March 2006. A jury will meet in April to judge the best photos, which will be exhibited at the Eurordis 2006 Membership Meeting in Berlin on 5/6 May. Prizes will be awarded to the best picture per category.

Prizes per category:

Category	Prize
Portrait of the person affected by a rare disease	Digital Camera Fuji F 10 6.3 MegaPixels Zoom 18.5 X
Care and treatment of the disease; managing the disease	DIGITAL Video Camcorder Canon MV 830i
Living together (patients with family, colleagues, friends etc)	Digital Camera Konica Dimage Z6 6 Megapixels Zoom 48X
Young photographers (photographs taken by people under 16 years of age)	MP3 Player IPOD Nano 2 GB

The competition is open to persons belonging to an organisation that is a member of Eurordis and immediate family members.

#### TIMEFRAME

1 January 2006: Start of the contest

31 March 2006: Deadline for entry submission

April 2006: Jury meeting

5/6 May 2006: Winners announced and photo exhibition in Berlin



Prize camera: Minolta Konica Dimage Z6

Please email your photo(s) and the entry form(s) to the following email address:

[jerome.parisse-brassens@eurordis.com](mailto:jerome.parisse-brassens@eurordis.com)

Or post them to the following

address:  
Jerome Parisse-Brassens  
Information Manager  
EURORDIS  
Plateforme Maladies Rares  
102, rue Didot  
75014 Paris  
France

**Deadline: 31 March 2006**

#### Technical requirements:

- Photos can be in colour or black & white;
- Digital images should be high resolution (recommended);
- Prints should be 13 x 18 (= 5x7 inch) minimum;
- Slides are not accepted.

Entry forms can be downloaded from:

[http://www.eurordis.org/IMG/doc/Entry\\_Form.doc](http://www.eurordis.org/IMG/doc/Entry_Form.doc)

#### For more information:

Contact Jerome Parisse-Brassens

e-mail: [jerome.parisse-brassens@eurordis.org](mailto:jerome.parisse-brassens@eurordis.org)



## The Dublin Leader Forum

### What is the Dublin Leader Forum?

The Dublin Leader Forum is a group for leaders that is run by leaders. A leader is somebody who uses a Personal Assistant service.

The Dublin Leader Forum is an independent forum which gives support to leaders. One of its main aims is to try to reduce the isolation felt by individual leaders. It also acts as a platform for sharing information. The Dublin Leader Forum advocates placing the leader in charge of their P.A service and their own lives.

The Dublin Leader Forum originated as an idea in 2004 and started up at the end of July 2005. It published its first newsletter last October.

On 24<sup>th</sup> February it will be holding a solidarity night for both leaders and PA's to interact socially in the West County Hotel in Lucan to which all Leaders in Dublin are invited.

For further information on the Dublin Leader Forum contact: Orlaith Humphreys at: [orlaithumphreys@dublincil.org](mailto:orlaithumphreys@dublincil.org) or Owen Collumb at [owencollumb@dublincil.org](mailto:owencollumb@dublincil.org)

## Wheelchairs Confiscated at Melbourne Shopping Centre

*We thought the following article may interest (or even shock) you!*

One of the world's top shopping mall owners has paid A\$50,000 (approx €32,000) to the Muscular Dystrophy Association of Australia after mall wheelchairs were taken from two brothers with the condition, forcing one to crawl to his car.

The other brother had to be carried to the car by his sister.

A security guard at a Westfield shopping center in the southern city of Melbourne stopped the brothers when they attempted to take the wheelchairs, which belonged to the shopping mall, outside.

"Westfield apologizes for the circumstances which led to the incident and deeply regrets the indignity suffered by the brothers," the company, which is the world's top shopping mall owner by market value, said in a statement.

Taken from: <http://news.yahoo.com>



Actor Brian Murray (aka Bob Charles in Fair City) rehearses for Valentines Day at an MDI Awareness Day photo shoot on the set of RTE's Fair City while Joe Mooney (Director, MDI) and actor Helen Roche (aka Emer Charles in Fair City) look on!