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## Editorial

Hi Folks,

Welcome to the first issue of our newsletter of the New Year. Hope you all had a nice break and best wishes for 2004.

With Valentine's Day just around the corner, this means MDI Awareness Day 2004 is also close to hand, therefore we are now looking for people (members, friends, retail outlets etc.) to sell chocolates and spread the word! This year, you can now text your order to 51123. For more details see page 2.

I always believed that if you really want to do something you can, if you have the right support, resources etc. And on page 5 there is an inspiring article about Michael McGrath who became the first person with a disability in the world to reach both the North and South Poles. Michael has limb-girdle muscular dystrophy.

Unfortunately this issue is not as full as I'd like it to be as we received very few articles, and no photographs. This newsletter belongs to you, the members of MDI, and to keep it this way, it is important that we receive articles etc. from you. Therefore, I would encourage members to send in anything that you think may interest others and make this newsletter yours! The next issue is due out mid March, therefore articles should be sent to me before 5<sup>th</sup> March and thereafter, the first week of every second month (e.g. May, July, Sept., etc.).

Also in this issue, because I haven't many articles, I have taken the liberty of advertising my debut CD entitled "Look Deeper" which was launched before Christmas. Check out page 7 for more, and tell all your friends to buy it!!

I hope you find something in this issue of interest to you, and remember, you can make it more interesting by contributing to it. So, get writing and I look forward to hearing from you.

Until next time, take care.

**Hubert McCormack**  
Editor

*MDI Awareness Day*  
*Valentine's Day 14<sup>th</sup> February*



*Lily O'Briens*

*Chocolates*

*Have A Heart*

*We would really appreciate*  
*your support*

*Check out page 2, for more on how you can help.*

## *Awareness Day*

*St. Valentine's Day, 14<sup>th</sup>*

*February 2004*



Muscular Dystrophy Ireland's third National Awareness Day will take place on St. Valentine's Day, Saturday 14<sup>th</sup> February 2004. As you are aware, the idea behind this initiative is to raise the profile of MDI

and to create further essential public knowledge about the condition of muscular dystrophy and the role MDI play.

To help achieve this, MDI will once again be selling two handmade heart shaped chocolates in attractive new red and white boxes appropriate to Valentine's Day. As before, chocolates will be sold at €2.00 each for a small box of two. Again, we need to secure retail outlets that will sell our chocolates and MDI are again seeking the support of members nation-wide to promote these chocolates and inform the general public about the condition of muscular dystrophy.

We would once again encourage members to get in contact with their employers, local retail outlets (shops, pubs, restaurants etc.), sports & leisure clubs, etc., with a view to taking a carton of chocolates (one carton = 42 boxes x 2 chocolates). We would also encourage members to contact their local media (newspapers, radio etc.) in order to promote this day.

MDI really rely on the support of members and friends in this regard, in order to make this campaign an even greater success than previous years. We would encourage members, even if only to take one carton, (to sell in your home to family and friends) to contact the office on freephone 1800 245300.

*Lily O'Briens*



*Sample heart shaped chocolates, sold in boxes of two for €2.00 each*

## *Have A Heart*

*We would really appreciate your support*

**Text MDI to 51123 to order today!**



*This year, we have also set up a service where people interested in selling chocolates can simply text in MDI to 51123. You will then receive a response requesting you to reply with your name & address so we can contact you.*

*Your support is appreciated and will make a difference.*

**See page 5 for another way to text today and support MDI**

*The following article is a summary of the MDI Chairperson's Report, which was presented to the MDI AGM, last September. For those of you who were not present at the AGM, this report paints a good picture into what has been happening in MDI over the last year.*

## **Summary of MDI Chairperson's Report, for 2003**

2003 was the European Year of People with Disabilities, and I am delighted to see that muscular dystrophy is becoming a greater part of public consciousness and that our organisation continues to go from strength to strength. This



*Jimmy Murray  
Chairperson - MDI*

has been achieved by an increase in funding from some health boards, various fundraising initiatives organised by members all over the country, and by MDI's second National Awareness Day. For all members who were out and about during our campaign, it was exciting to see how the general public recognised MDI. Awareness is continuing to grow nation-wide as a result of increased fundraising efforts by our branches and I must congratulate all concerned for giving their time towards their respective projects. Work has already begun on the Awareness Day 2004 and we hope to have new ideas to keep the profile of MDI high.

2003 has seen the establishment of two new branches, in Kerry and Kilkenny and our staff are always available to offer support with their activities, should it be required. MDI would not be in as strong a position as it is now without the support of branches and members at a local level, and I look forward to seeing more members becoming actively involved.

With new personnel joining MDI over the past year, the services available to MDI are expanding and improving. An increase in the number of Family Support Workers means that each have a smaller area to cover and can therefore spend more time supporting members.

In relation to our Youth Services MDI have also appointed two additional Youth /Respite Workers in 2003.

These appointments have increased the services that MDI provides, including information, respite, youth activities, transport, a regular newsletter and our website, and these are constantly being updated and improved.

MDI had five summer breaks in 2003, including the younger teenagers' camp which took place from the 19<sup>th</sup> to the 26<sup>th</sup> of July in Kilcuan in Galway and the Spanish Exchange Programme took place from the 20<sup>th</sup> to the 28<sup>th</sup> of August in UCD which was a great success.

2003 also saw the introduction of a new activity for the younger members. Our Youth Workers organised a power soccer day this summer, which was attended by members from the eastern, southern, western and midland regions. There is huge interest in this game, and it will be great to see how it develops. Maybe before long we will have an MDI national power soccer league.

Karen Jameison, our National Information Officer has visited many Health Boards last year, making presentations to physical and sensory co-ordinating committees informing them on the condition Muscular Dystrophy and on the services that we provide for our members. MDI could not provide these services without the financial assistance from the Health Boards around the country, and I must acknowledge their support. MDI has received an additional 316,466 Euro from the Northern Area Health Board towards core staff and the rent towards our new office in Dublin.



As I reported in 2002, MDI has expanded over the year 2001-2002 and as a result so too has our staff numbers. We recognised the urgent need for a more spacious Dublin office and secured new premises in 71/71 North Brunswick Street, Dublin 7. We took up occupancy in October 2003. These offices have created a more comfortable working environment for all our staff and allow greater access and privacy for members visiting. I would like to thank the Carmichael Centre and its staff for the tremendous support they have given to MDI over the last 14 years.

Part of our mission statement is to fund research and MDI are currently funding Professor Ohlendieck's research into the role of calcium in Duchenne MD. This project is funded over a three-year period and we look forward to their final report on the findings.

I would like to thank the Disability Federation of Ireland, the Neurological Alliance of Ireland, the European Alliance of Neuromuscular Disorders Association (EAMDA) and the European Organisation for Rare Disorders (EURORDIS). The Special Olympics last year was a tremendous success in raising awareness of disability among the government and the general public. Mary Davis, CEO of the Special Olympics and all those who gave their time to ensure that the games were a great success and enjoyed by all truly created real awareness of disability with every citizen in the country. It demonstrated that disability is an important sector of our community and must be recognised as so. I am hoping that this will be reflected in the re-drafted Disability Bill. We will continue to work with the above organisations to ensure that issues affecting people with muscular dystrophy and other disabilities remain a priority for government, and that the public awareness is continued and increased.

I would like to extend thanks to Dr. Brian Lynch and his team at the Central Remedial Clinic, and to Dr. Orla Hardiman and her team at Beaumont Hospital, for their expertise in running the clinics for young and adult members.

Our main endeavour is to provide support and information to people with muscular dystrophy and their families. We are meeting this aim together, with the personnel employed by MDI, volunteers, the local branches, sub-committees, National Council and National Executive and sub-committees.

I wish to thank John Handibode and his colleague Sheila for handling our accounts in their usual professional manner.

Thanks to our Director Joe Mooney who as usual has worked way beyond the remit of his position to ensure the delivery of services for our members both in times of crisis and also in our social activities.

In conclusion I would like to pay special thanks to all the volunteers who give so much of their valuable time to MDI, your Vice-Chair Ursula Hagerty, Treasurer Joe Jameson, Secretary, Hennie Walsh, and fellow Executive member Florence Dougal.

Thanks to both members and personnel for your work over the past year, I expect 2004 will be as successful and rewarding.

## ***Reminder***

We would like to remind members that we have two work stations situated in the meeting room at our new offices which are available to members, should you wish to use them.

If members wish to use a computer, or pop in to see our new premises, please phone in advance and let us know.

We look forward to seeing you.

## Poles Apart!

At midnight on 13<sup>th</sup> January 2004, Michael McGrath became the first person with a disability in the world to reach both the North and South Poles. Michael has limb-girdle muscular dystrophy and embarked on a two year mission called pole2pole, to raise funds for the Muscle Help Foundation.

After conquering the North Pole, Michael and his team set off on the second leg of the trip on New Year's Day to reach the South Pole. This is an excerpt from the team diary:



Michael McGrath

*13 January 2004:*

The team arrived at the South Pole at mid-day today UK time (midnight local time), after pulling Michael in his wheelchair and strapped securely to a sledge, across the ice for 5km in temperatures of wind chill factor -46 degrees. He walked assisted by Miles Peckham for the last 310 metres as he did at the North Pole, each metre representing 10,000 people with muscular dystrophy worldwide. This is a courageous and difficult challenge and we must not forget the obstacles they have had to overcome in their efforts to raise awareness and £1 million for neuromuscular disorders.



Taking 45 minutes to walk 310 metres  
One metre for each 10,000 people with MD worldwide



Michael McGrath and transport at the symbolic South Pole

Michael himself said "Reaching the South Pole and completing the pole2pole expedition means so much to me – not just from a personal perspective of confronting head-on the challenges presented by my condition. Our aim was to raise awareness and funds for research into muscle disorders by highlighting what people can do, not what they can't".

*The Muscle Help Foundation aims to promote a global awareness of muscle disorders and to fund high calibre research into neuromuscular conditions. For more information about the Foundation and the pole2pole expedition, please see [www.musclehelp.org](http://www.musclehelp.org)*

## Reminder

MDI would like to thank everyone who sold or supported us in our sale of Christmas cards in December.

Your support is much appreciated. If you have not yet returned the proceeds, we would be grateful if you could do so at your earliest convenience.

Thank you.



## Duchenne Research Updates

*There are two articles that will be of interest to anyone wanting to know more about research into Duchenne muscular dystrophy.*

- [Research Approaches Towards a Cure for Duchenne Muscular Dystrophy](#)

Guenter Scheuerbrandt PhD has written this very informative article covering all of the different types of research. A positive point about this article is that it will be updated in autumn 2004 and approximately once a year after that. It is well written and can be found at:

[www.duchenne-research.com/home-en.htm](http://www.duchenne-research.com/home-en.htm)

You can also reach this page via a link on the MDI website in the research section.

- [Novel Therapies for Duchenne Muscular Dystrophy](#)

This article was published in the Lancet Neurology journal in May 2003, written by Australian doctors Robert Kapsa, Andrew J. Kornberg and Edward Byrne. While not quite as accessible for the general reader as the previous article, some people might find it interesting. It can be viewed through the Duchenne Parent Project USA website at:

[www.parentprojectmd.org](http://www.parentprojectmd.org)

Anyone who does not have internet access can get a copy of these articles by contacting Karen in the Dublin office on 1800 245300 or emailing [karen@mdi.ie](mailto:karen@mdi.ie)

### For Sale

#### Wheelchair Accessible Van

1999 Fiat Ducato with 53,000 miles. €11,000

**Spec includes:** \*Air Suspension and Ramp, \*Wheelchair tracking with tie-downs, \*10 rear seats (can be removed to accommodate people in wheelchairs), \*Rear Heater

For more details phone Anne at Enable Ireland Tallaght Services, Telephone: (01) 413 7725

## News from Galway

### Galway Get on Board

On 13<sup>th</sup> November 2003 I attended a Disability Information Day which was held in the Radison Hotel in Galway. The event entitled "Galway Get on Board" was organised by the Galway Centre for Independent Living and included various stands about disability organisations. Gary McMahon from the Galway City Council gave an opening speech and welcomed everyone. John Tierney, Galway City Manager spoke on the "Barcelona Declaration", which, among other issues, also specifies that pavements and roads should be accessible for people with disabilities. On the day, three able-bodied people from Galway, including Senator Margaret Cox, participated in a "becoming disabled for a day" project, to show how disability unfriendly Galway is. Following a discussion about wheelchair accessibility in Galway and what needed to be done, the day then concluded. I found the day to be both very informative and interesting.

### Conference on Disability, Relationships and Sexuality

On Saturday 11<sup>th</sup> October 2003, I attended a Conference on the topic of Disability, Relationships and Sexuality, which took place in the Holiday Inn Hotel, Pearse Street, Dublin. The Chairperson for the day was Mr. Niall Crowley, from the Equality Authority and guest speakers included Mr. Tom Shakespeare from the University of Newcastle, who spoke on disability and sexuality in the Irish context. We then heard from two disabled people, one of which was gay and he spoke of his struggle of being disabled and gay. There were five workshops in the afternoon, all to do with different aspects of disability and sexuality. Following the workshops the various individuals gave feedback. The Conference concluded at 4.00pm and I found the day very interesting.

*Eileen Gormley - Galway*

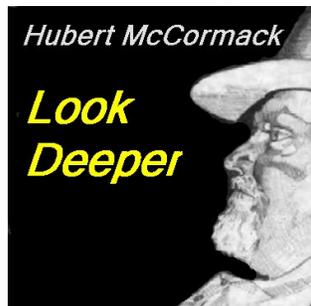
As editor of the MDI News Update, I have taken the liberty of acquiring a space in this issue of the newsletter for the following reasons:

## 40<sup>th</sup> Birthday Party Donations

Firstly, I would like to publicly acknowledge and thank my family, friends and colleagues for raising a total of €590.00 for MDI, by way of donations (*instead of birthday presents*) at my recent 40<sup>th</sup> Birthday Party. Thanks a million to everyone who made a donation and I hope you all had a good night.

## My debut CD – Look Deeper

Secondly, some of you are probably aware that in December 2003, I released my debut CD, entitled "**Look Deeper**", which features fourteen tracks, twelve of which are original.



Most of my songs examine and refer to personal experiences, attitudes and opinions, while growing up as a person with a physical disability. "**Look Deeper**" also highlights issues of real importance to me and, I hope, to fellow disabled and non-disabled people alike. I would describe my style of music as folk/ballad, with a touch of country. For more details check out my new website: [www.hubertmccormack.com](http://www.hubertmccormack.com) where you can listen to snippet recordings of my music and, if you like what you hear, you can order a copy of my CD. My CD is also on sale in Dolphin Discs, (Moore St. & Talbot St.), Dublin and in Road Records, Fade Street, Dublin, (back of George's St. Arcade).

I look forward to hearing from you.

Cheers,

**Hubert McCormack**

Support MDI in a Novel Way  
Send a Text Today!



## Text MDI to 53123

before or on Valentine's Day and receive a chat up line or Valentine Rhyme.

During the run up to Valentine's Day, people can text MDI to 53123 to receive a chat up line or Valentine Rhyme.

**Example:** Text MDI to 53123.

**Response:** "*Hi! You must be very tired, coz you've been running through my mind all night. Please support the MDI Valentine's Chocolate Appeal.*"

Share of the proceeds from the cost of your text go to MDI.

*Calls cost 50 cent*

## Get Texting !!!



# MDI News Update



*Two monthly newsletter - Issue 15, January 2004*

*Membership subscriptions for 2004 are now due. 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

<b>Name:</b>	<b>Date:</b>
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<b>Address:</b>
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<b>Telephone Numbers:</b>
Home: _____ Mobile: _____ Work: _____
Email Address: _____

<i>Please tick whichever of the following applies to you:</i>			
Person with MD	<input type="checkbox"/>	Family Membership	<input type="checkbox"/>
Friend of MDI	<input type="checkbox"/>		

<i>Annual Subscription Rates</i>	
Person with MD	€15.00
Family Membership	€20.00
Friend of MDI	€15.00

If you would like to make a donation additional to the membership fee, please indicate the amount here € _____
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<b>To enable us to update our records we would appreciate it if you would provide the following information regarding your family if applicable:</b>		
<b>Name(s) of Person(s) with MD</b>	<b>Date(s) of Birth</b>	<b>Type of MD</b>
_____	_____	_____
_____	_____	_____
_____	_____	_____

<p><b>All cheques and postal orders should be made payable to Muscular Dystrophy Ireland.</b>  <b>It is also possible to pay your subscription by Bank Giro to our account;</b>  <b>Muscular Dystrophy Ireland Savings Account at Bank of Ireland, 2 College Green, Dublin 2.</b>  <b>Branch Code 90-00-17 A/C No: 75261619</b></p>
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<p><b>Please complete this form and return it, with the relevant membership fee (see above) to:</b>  <b>Muscular Dystrophy Ireland, 71/72 North Brunswick Street, Dublin 7</b></p>
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