



MDI News Update



Two monthly newsletter - Issue Three, January 2002

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Editorial

Hello

Welcome to our first issue of the *MDI News Update* for 2002. I hope you all had a lovely Christmas and a New Year.

At MDI, we are well back into the swing of things and getting ready for the launch of our National Awareness Campaign which will take place on St. Valentine's Day, 14th February 2002. It is proposed that this date would then become established as MDI's Annual Awareness Day in subsequent years. More details in this issue.

Since our last issue, MDI have recruited a new Information Officer, Karen Jameison. We welcome Karen aboard and wish her well in her new post (see page 3 for more).

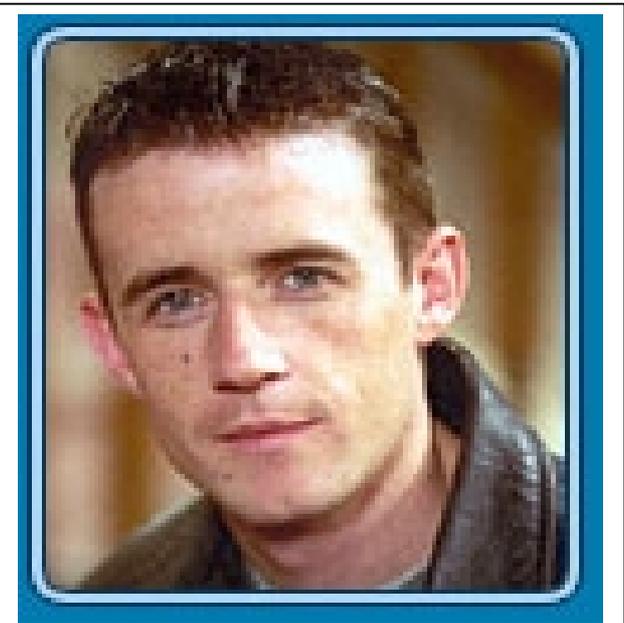
Also included in this issue among other things, is a short piece about the Family Support Service; details of an Information day in Belfast for Adults with Myotonic Dystrophy; and the establishment of a new Driving Assessment Centre in Mayo, for people with limited mobility.

As always, we are constantly looking for articles to include in each issue. This is an ideal opportunity for our branches and members to publicise events and share or comment on experiences which may be of interest to fellow members. If you have any contributions for any future issues, please send them to us before the first of every other month (e.g. 1st March, 1st May, 1st June etc.) in order to be included in that month's issue.

Finally, I would like to take this opportunity of wishing everyone a Happy New Year.

Enjoy.

Hubert McCormack



David Mitchell, known to many as Jimmy Doyle, in RTE's popular TV soap "Fair City" and other members of the "Fair City" Cast will be supporting MDI's Awareness Day, which will take place on Thursday 14th February 2002. Valentines Day.

Director's Note

Hi All,

I'd like to take this opportunity to wish you a Happy New Year. I look forward to a challenging year ahead with MDI. One of the major challenges for 2002 is to create a greater awareness of muscular dystrophy and the role MDI plays. Therefore, we have organised an Awareness Campaign, which will kick off in February. I am seeking the support of all members of MDI to help make this project a success.

Joe T Mooney - Director MDI



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MDI Awareness Day

14th February 2002

Muscular Dystrophy Ireland are organising a National Awareness Campaign over the coming months. The key area of this campaign is to have a National Awareness Day, which will take place on St. Valentine's Day, 14th February 2002.

This date will become established as MDI's Annual Awareness Day in subsequent years.

The idea behind this Awareness Day is to raise the profile of MDI and to create a greater public understanding about the condition of muscular dystrophy and the role MDI play.

To help achieve this, MDI has secured a product to sell on the day. This will be a beautifully packaged box with the MDI logo, containing two handmade chocolates from Lily O'Briens, which will be sold at a cost of €2.00. It is necessary to secure retail outlets that will sell this product.

MDI are seeking the support of branch members to promote this product and inform the general public about the condition of muscular dystrophy. If any members are interested in this area, contact the office for more details. We also would encourage members to get in contact with your local retail outlets and local media (newspapers, radio etc.) in order to promote this day.

To mark the close of MDI's National Awareness Day, a concert is being organised for Valentines Night, which will take place in the Royal Dublin Hotel, O'Connell Street, Dublin, featuring an

unaccompanied four part harmony group, The Parson's Nose and Friends. Singer / Songwriter Christy Moore will make a special guest appearance on the night. Tickets are priced at €15.00. The venue accommodates approximately 180, therefore early booking is advisable.

There will be a national launch of the Awareness Day in February and we are seeking national press coverage for this launch. MDI are also seeking support from television personalities to promote the day.

How you can help

*Beautifully packaged boxes
with the MDI logo,
containing two handmade
Lily O'Briens heart shaped
chocolates will be sold
nationwide on
Valentine's Day,
14th February 2002 for €2.00*

*MDI are looking for retail
outlets to help sell these
chocolates.*

*Perhaps you can contact
your local shops, pubs etc.
and ask them to take a box.*

**WE NEED YOUR
SUPPORT**



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New Information Officer



My name is Karen Jameison and I have been working with MDI as Information Officer since November 2001. I come from Co. Down but have been living in Dublin since 1994. In 1998 I graduated from Trinity College with a degree in Psychology and English Literature and moved on to the Royal College of Surgeons where I was doing research into depression.

Since I started working with MDI I have been collecting and updating information on neuromuscular conditions. Anyone who requires information, whether it is on specific conditions, current research, the services MDI offer or benefits and entitlements, can contact me at the Dublin office. I'd be more than happy to hear from you.

I can be contacted by phoning 1800 245300, or by writing to Karen Jameison, Muscular Dystrophy Ireland, Carmichael Centre, Coleraine House, Coleraine Street, Dublin 7. You can also email me at info@mdi.ie

MDI would like to welcome Karen on board and wish her well in her new position.

Family Support Service

Most of you are probably aware of the Family Support Service that MDI provides to our members. For those who may not be aware, briefly, MDI employs five Family Support Workers (FSW's) whose role is to visit members in their own homes and to identify, evaluate and advise on the problems that arise with neuromuscular conditions. The Family Support Worker also provides information on the various neuromuscular conditions and on welfare issues which are not always readily available to families.

If you ever need to contact the Family Support Worker for your area, you can now do so by contacting them directly on their mobile (see below). You can also phone our Dublin office on freephone 1800 245 300 if you are having difficulty and we will try to contact them for you.

FSW: Helen O'Brien
Area: East
Hours: Monday - Friday 9-5
Phone No: 086 6066108

FSW: Caroline Moran
Area: West, North West, Midlands
Hours: Monday - Friday 9-5
Phone No: 086 6066106

FSW: Catherine Jones
Area: North East
Hours: Mon, Tues & ½ Day Wed
Phone No: 086 6066105

FSW: Marie Kealy
Area: South East
Hours: Mon, Tues & ½ Day Wed
Phone No: 086 6066107

Mary O'Sullivan, FSW for the South and Mid West is currently on maternity leave. In the interim, you can contact Mary Rose Howell, Youth Worker for this area. Her number is: 086 6066104, Mon-Fri, (9-5) or contact the office at 1800 245300.



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Branch News

Cork News

The Cork branch had its annual Christmas dinner on Sunday 9th December in Jurys Hotel. Some people travelled long distances for the occasion, and it turned out to be a great success.

The Cork children's Christmas party was held on Sunday 16th December in the Blarney Park Hotel. Santa and Mrs.. Claus arrived on the day with big bags of presents for everyone!! Santa's helpers came too, and played games all day. A great day was had by all!!!



Cork Children's Christmas Party

Corks Youth Group is still up and running. Our recent meeting took us to see "Babes in the Wood" at the Everyman Palace theatre on the 12th January. If anyone has any ideas on what they would like to do next, let Mary-Rose know!!!



Members of the Cork Youth Group who went Bowling in Leisure Plex for their first meeting.

A charity table quiz is to be held on Wednesday 6th February in the Muskerry Arms, Blarney, Cork. All are welcome to attend. Tables are to a maximum of 4 people. Great prizes guaranteed!!! For more details phone the Cork office 021 - 4309047.

Kerry News



Aoife and Patrick Flanagan pictured at the Children's Christmas Party Kerry

The Kerry Christmas party was held on Friday 21st December in the Killarney Court Hotel. Santa arrived here too, with presents for everyone. Everyone had a great day!!

Midlands News

Midlands baby boom: congratulations to the new mums and dads.

Well done Breda Brennan for winning the Leinster final of the Carer of the Year Award.

Thanks to the Branch for organising a christmas outing in Goffs, Kildare a great day was had by all. (See page 6).

Donegal News

A big congratulations to Darren McDonagh who won a child of achievement award from Share A Dream and got to go to EuroDisney with his family. RTE were so impressed with Darren that they sent the Nationwide team to Darrens home to let the people of Ireland know how courageous Darren has been.



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Galway News

We had a very enjoyable Christmas get together with the young Galway members. Thanks everyone for making the day such good fun.

Thanks to everyone for making it out for the adults Christmas get together it was great to see everyone together again.

It was good to see the Western Health Board in December recognise the international year of the vounteer and the work carried out by two MDI volunteers Kathleen Healy and Adrian Walsh. Thanks for your continued support and the support of the Mountbellew Branch.

All Aboard For Santa's Kingdom

When it came to celebrating Christmas this year, the Midlands Branch wanted to do something a little bit different. We heard about Santa's Kingdom which was coming to Goff's in Co. Kildare and decided to go for that. Having obtained tickets (an achievement in itself), we all met up in the Ambassador Hotel on Sunday 9th December and then crossed the road to Goff's and into a totally different land.

We boarded a shuttle which brought us to the cave where the Ice King and Queen lived and there we met the elf who was our guide to the kingdom. He brought us through to the workshop where the other elves were busy making all the toys that would be needed for Christmas. We watched them being made, painted and finally we where shown where they went along the conveyor belt to be packed. The conveyor belt had stuck so we had to

go to call Mr. Grumpy out of bed to fix it so that the work could continue.

While he did this, we continued to look around the village, seeing the elf's houses and then we went into Santa's house where we met Mrs. Claus. Afterwards, we went to see the reindeer in their stables. Our elf guide explained that the antlers and Rudolf's Red nose only came into operation when the journey began on Christmas Eve.

Then it was off to the snow playground where we enjoyed throwing snowballs, sliding down the snow slopes and a playground for the smaller children.

Finally, it was our turn to meet Santa himself where each child got a small gift and a certificate to shown they had been there. It was a very happy and tired group that left the kingdom.

Overall it was voted to be a very enjoyable evening and one that both children and adults will remember for a long time to come.

**Brendan McElligott
Midland Branch - MDI**



Pictured with Santa on a surprise visit to the McAuliffe household in Kanturk on 21st December last are Keith, Sharon and Ieshia McAuliffe.



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Dublin News

The Dublin Branch Children's Christmas Party was held on Saturday 15th December in Carmichael House. A very enjoyable day was had by all and Santa delighted the children with his presence.

On 1st December, after the last National Council Meeting, a presentation was made to former Chairperson of MDI, Judy Windle, for her hard work a dedication over the years. We wish her well in the future.

The Ladies Support Group held their annual Christmas Dinner on 12th January in the Arlington Hotel, Dublin. A really good day was had by all.

Information day for Adults with Myotonic Dystrophy

"An information day for Adults with

Myotonic Dystrophy

will be held on

Saturday 2nd March 2002

in the

Fitzwilliam Hotel, Belfast International Airport, Crumlin.

For a booking form or for more information contact the MDI Office on freephone 1800 245 300.

Alternatively, you can contact:

Oonagh Morrison
Muscular Dystrophy Campaign,
Forster Green Hospital,
110 Saintfield Road,
Belfast BT8 4HD.

Tel: 028 9079 0708

Email:

oonaghm@muscular-dystrophy.org/

New Driving Assessment Centre

The Disabled Drivers Association has recently established a new Driving Assessment Centre at their offices in Ballindine, Co. Mayo.

Equipped with the latest technology the Ability Static Assessment Unit includes the following tests:

- Steering Wheel Load and Ability Test;
- Accelerator Modulability Test;
- Break Load Test;
- Acoustic Reaction Test;
- Visual Reaction Test;
- Choice Visual Reaction Test;
- Visual Field Tests;
- 9/18/27 Variable Lamps Reaction Test.

The Unit provides accurate testing using various technical adaptations for people with disabilities.

The unit will be of particular benefit to people with restricted limb movements.

The test sequence is designed to identify the person's strengths and weaknesses and by the use of various technical aids/adaptations identify suitable solutions to enable the individual to drive in a competent and safe manner.

For further information or details contact:
Derek Farrell, Centre Manager
094 64054 or 094 64266.

Reminder

To anyone who sold Christmas cards and have not yet sent in the proceeds, could you do so as soon as possible.

Thank you for you continued support



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MDI Foroige Youth Club

Hi. My name is Steven Valentine and I have been organising and running the Youth Club in the Eastern Region for the last two months. At the moment the Youth Club caters for members under the age of 18 years.

The club was revitalised recently by a visit from Colin McAree, Regional Youth Officer from Foroige who attended a meeting with some of our members. The meeting explored ideas and activities for the future and Colin offered Foroige's ongoing support.

Since this meeting, we have had three successful youth club trips involving games of Boccia (a type of bowls), Ten Pin Bowling and a trip to the cinema to see Harry Potter. We also had a Christmas Shopping day out!

We try to accommodate a variety of tastes and welcome any ideas you may have for future activities. Please let me know if there are any activities or trips you would be interested in. You can contact me in the MDI office on 1800 245 300. I look forward to hearing from you.



*Stephen Valentine
Youth Worker - MDI*

Accessible in Canada



I returned to Canada this Christmas after 12 years. My family and I spent 4 days in Toronto before going on to Huntsville to stay in the Deerhurst Hotel. We travelled from Dublin Airport to Heathrow then on to Toronto Airport. In the latter there was someone waiting to bring us through so I did not have to queue. The taxi was very comfortable and equipped for my electric wheelchair with plenty of room for my family and our luggage. The hotel catered very well for people with disabilities with easy to use lift doors etc and the staff were very willing to help.

Going out was very easy as shops, clubs, pubs etc all are wheelchair friendly and it seems that the whole system in Canada is far in advance of Ireland in the planning and application of accessibility issues. An example of attitude came in the airports where in Canada every effort was made to ease the transition from my electric chair to a pushchair for the plane; in Ireland and England I was made to feel something of a nuisance.

The journey was tiring anyway but with a little thought from people on this side of the Atlantic it would have been easier on my family and myself. We did enjoy seeing relatives again and a white Christmas!

Steven Valentine



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Membership subscriptions for 2002 are now due. If you haven't already paid your subscription this year please complete this form and return to the address below by 1st March 2002.

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

Annual Subscription Rates	
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