RTE’s Fair City cast help launch MDI Awareness Campaign 2007

Kevin Gannon, (10) & Jason Connelly, (14) MDI members pictured with David Mitchell (aka Jimmy Doyle, Fair City) and Maclean Burke (aka Damien Halfin, Fair City) in the Bistro on the set of Fair City at the launch of Muscular Dystrophy Ireland’s annual Have A Heart Awareness Campaign.

Photo: John T Ohle

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Enjoy!

Hubert McCormack
Editor

Muscular Dystrophy Society of Ireland Ltd., 71/72 North Brunswick Street, Dublin 7.
Ph: 01 8721501 / 872 3826 ● Email: info@mdi.ie ● Website: www.mdi.ie
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New Trial to Evaluate Steroids in Duchenne Muscular Dystrophy

Some 300 boys worldwide with Duchenne muscular dystrophy will be invited to participate in a multinational study of three corticosteroid regimes. Although corticosteroids have been used successfully for a number of years, there is still debate about which steroids to use, what the dose should be, on what schedule and for how long.

This new trial is set to launch in 2008, under the guidance of the principal investigators: Kate Bushby, Professor of Neuromuscular Genetics in Newcastle, UK and Robert Griggs, Professor of Neurology in the University of Rochester, New York.

Three regimens will be tested using both prednisone and deflazacort in boys aged 4-7 years old and will last for at least three years. Children’s muscle and respiratory functions will be examined, as well as parental satisfaction with the treatment.

Clinical Trials

There is a range of clinical trials currently taking place throughout the world relating to different types of muscular dystrophy and other neuromuscular conditions. You can view these on the website: www.clinicaltrials.gov. When you go into this website, you will see a search box and you can enter in here the type of condition you are interested in. You can also select whether you would like to view the trials that are currently recruiting, or those that are in progress or completed. Each trial has an estimated completion date, so it is worth checking the website to see what progress has been made and if there are any results available.

Don’t worry if you do not have internet access, I will keep you updated on completed research as it happens.

Chip and PIN Day

17th March 2007

Chip and PIN was introduced to Ireland in 2004 and since then, signing a receipt when using your credit or debit card has been gradually phased out in favour of using a four digit PIN - personal identification number - to improve security and limit credit card fraud.

At the moment, if you have a Chip and PIN card, you can still choose to sign rather than entering your PIN. However, from 17th March, which has been designated PIN day, anyone using a Chip and PIN debit or credit card will no longer be given the option of signing for purchases.

It has been recognised however, that some people with disabilities are unable to use Chip and PIN cards independently. In this case, you can contact your bank or credit card company and ask for a Chip and Signature card. When the card is inserted into the machine when you make a purchase, it will inform the cashier that your purchase can be verified by signature rather than a PIN. Applying for this card may take a couple of weeks to process so you should make this request as soon as possible.

A Date for your diary

The MDI Annual General Meeting will take place on Saturday 28th April 2007 at the Heritage Hotel, Portlaoise at 2.30pm

Prior to the AGM, there will be a number of speakers on the topic of Research into Muscular Dystrophy.

Further details will be sent out in the coming weeks.
Muscular Dystrophy Ireland would like to thank everyone who supported us throughout our National Awareness Campaign 2007, which as usual centred around the selling of heart shaped Lily O’Brien’s chocolates on Valentine’s Day. This was MDI’s sixth year to promote awareness of the condition through the selling of chocolates and securing Press, Radio and TV coverage nationwide. It was our most successful campaign to date and MDI would like to thank members, staff and volunteers who got involved. Without your ongoing support, time and energy we would not have exceeded last years profits of €71,000.00 which it looks like we will this year, when all proceeds have been returned.

In the left corner! Katie Taylor, world lightweight boxing champion helping to promote chocolate sales with Steven Valentine, MDI.

A special thanks to:

Our Sponsors:

Spar
Interlink
Fastrack
Budget Travel
Debenhams

Our Promoters:

Fair City Cast
For supporting us every year to date. Once again thanks a million

Martin King
TV3 Weather Man & D.J., for launching this years campaign

Katie Taylor
World lightweight boxing champion - for “pulling the punches for MDI”

Marcella & Ronan Gavigan & Dr Brian Lynch, CRC
Who appeared on the Afternoon Show on RTE 1- Monday 12th February

Rita & Jason Connolly & Jane Dawson (Physiotherapist CRC)
Who were interviewed on Ireland AM on TV3 - Tuesday 13th February

Pictured at the launch of MDI’s Awareness Campaign are: TV3 weatherman Martin King, MDI Dublin branch member Simon Jameson and Safann McCarthy, Marketing Manager, Spar. 

Photo: John T Ohle
On behalf of the members, families and friends of Muscular Dystrophy Ireland in the North West region, I would like to thank everyone in Donegal, Sligo & Leitrim who helped out and got involved in this year’s MDI National Awareness Day 2007.

Special thanks is extended to Kevin Harrison (MDI member Leitrim) Moira Lavin (Sligo) Imelda Quinn (Liford) & all the families and friends of the Muscular Dystrophy branch Donegal, Ann Conlon (Sligo) Margaret Harkin (Leitrim) Georgina Reddin (Sligo) and everyone who gave their time and supported me with this year’s Awareness Campaign. I would also like to thank Karen (Tesco Ireland) and all at the Tesco Arcade in Sligo for their continuing support in allowing us to erect our information stand which was kindly provided to us by Catherine & Pat of Sligo Youth & Community Services. As can be seen from our photos we had a very enjoyable & successful Awareness Day.

Again, many thanks to everyone who participated in this year’s event.

Fintan Flannery
Family Support Worker - North West Region

The deadline for receipt of articles, photographs etc for the next MDI newsletter is Friday 4th May 2007. Please send your news to Hubert McCormack at hubert@mdi.ie
On Feb 14th MDI staff and members were selling chocolates in Debenhams to help raise awareness. We started selling chocolates at 10:00 am. By the time we stopped at 17:00 we had sold out of chocolates! We were busy all day and pleased to report that lots of people mentioned the recent T.V appearances by members. On behalf of Muscular Dystrophy Ireland, myself and Lisa Fenwick (Family Support Worker) we would like thank all those that helped on the day, in particular Eileen Gormley, Patricia Hannon, Teresa Conboy and Saorise Flynn who so generously gave up their time to help.

Aisling Dermody
Youth & Respite Worker
Western Region

WANTED
Hi-Lo Electric Bed for MDI member in the South East. If you know of someone who can help phone: 086 8384428 (between 9am-5pm, Mon-Wed)

New MDI Driver
MDI would like to inform all members that a new MDI Driver has been appointed for the Eastern Region. Robert Dowd commenced work with MDI on Monday 26th February 2007. We would like to welcome Robert to MDI. If you require transport for hospital appointments, clinics, etc, you can contact Robert on: 086 3899262 or contact the MDI office on 1800245300. Please note that it is important to book in advance.
Hi everyone,

Aisling Dermody here (Youth & Respite Worker for the Western Region). Below is a short note to update you on recent news and activities of the Youth and Respite services.

**Activities**

MDI Youth Clubs and Playstation Tournaments have taken place on several occasions since Christmas. Some of these included a day trip to Athlone for lunch and bowling, where members from Roscommon, Westmeath & Offaly attended and had a great day. There was also a day out in Port Laois where seven members enjoyed lunch and a trip to the cinema. For some members it was their first outing with MDI and there will be more days out soon.

This year’s power soccer tournaments have started. To date, there have been tournaments in Dublin and Limerick. It is also planned to have one in the midlands, date not yet confirmed.

The Youth & Respite workers are currently busy planning the first camp of this year, due to begin on 30th March. This camp will take place in Kilcuan Lodge, Clarinbridge, Co. Galway.

**Personnel**

On behalf of MDI and fellow Youth & Respite Workers, I would like to welcome Emma Carass, the new Youth & Respite Worker, who will be covering the North East Region. We would also like to wish former Youth & Respite Worker for this region, Brenda Hopkins all the best in her new employment.

We would also like to congratulate Karen Leonard, Youth & Respite Worker for the Eastern Region on her recent marriage to Ronan and wish them well in the future.

_Aisling Dermody_
_Youth & Respite Worker_
_Western Region_

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**New Youth / Respite Worker**

**North East Region**

Hi everyone

My name is Emma Carass. I am from the parish of Boardsmill, in Co. Meath where I grew up with four brothers. At present I am living in Trim, Co. Meath.

I have recently been appointed as the Youth / Respite Worker with Muscular Dystrophy Ireland for the North East Region, which covers Louth, Meath, Monaghan and Cavan.

After my Leaving Certificate I studied Art and Design in Colaiste Ide, in Finglas, and following on from this I spent a year studying Design in D.I.T. in Mountjoy Square, Dublin.

During College I did volunteer work with a Foroige youth club and with the T.I.D.E. project in Trim, Co.Meath, working on Summer Camps and in an After-schools programme.

Once finished at college I worked at T.I.D.E. on a full time basis in a community creche. Following on from there I worked in Bright Horizon's a Creche in Blanchardstown. I worked primarily with babies aged 3 to 15 months. I worked for 3 years, spending one of those years working at one of the companies creches in Aberdeen, Scotland.

For the last year I have been working for the Daughters of Charity, in a special needs school, where I worked mainly with children with autism.

I am really looking forward to my new position with MDI and to meeting the members and their families in the near future. I can be contacted at: 086-6066108 or 046-9280026.

MDI would like to welcome Emma on board and we wish her well in her new role.
**Respite Research Project
Needs Your Help**

The HSE is funding research to be carried out by the Irish Association for Spina Bifida and Hydrocephalus, in partnership with Muscular Dystrophy Ireland (MDI) and Freidrichs Ataxia Society of Ireland (FASI), to establish the level of need for centre based respite care among people living with the conditions listed above.

There will be six focus group meetings held around the country, two in each of the following regions:

**Limerick**
Jury’s Hotel, Limerick
Wednesday 18th April 2007

**Meath/Cavan/Monaghan**
Newgrange Hotel, Navan
Tuesday 24th April 2007

**Dublin**
The Royal Dublin Hotel
Thursday 26th April 2007

In each region there will be one focus group for people with disabilities and one focus group for friends/family members.

All focus groups will be independently facilitated.

It may be necessary to randomly select participants but the aim is to include as many people as feasible.

A Questionnaire will also be circulated to all members in early May.

The better the response, the better the research. Therefore, MDI would urge all members to participate by lending your time and support. Wherever possible, your transport to and from the focus group meetings will be compensated. Tea/coffee and sandwiches will also be served.

**Members of MDI who wish to take part in a focus group can contact Kate Power at 01-872 1501 or email kate@mdi.ie. People who are not members of the organisations are also welcome to participate and can contact the independent researcher directly on: 087-6823530 or email nuala.taft2@mail.dcu.ie.**

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**MDI Youth / Adult Camps 2007**

The dates for this year’s MDI camps are as follow:

<table>
<thead>
<tr>
<th>Date</th>
<th>Age Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>31st March – 5th April 2007</td>
<td>15-18 year olds</td>
</tr>
<tr>
<td>14th May – 20th May 2007</td>
<td>over 25s</td>
</tr>
<tr>
<td>21st July – 27th July 2007</td>
<td>11-15 year olds</td>
</tr>
<tr>
<td>3rd September – 9th September 2007</td>
<td>18-25 year olds</td>
</tr>
</tbody>
</table>

All camps will be held in Clarenbridge, Co Galway. For more information regarding these camps etc., contact Kate Power at 01-872 1501 or email kate@mdi.ie.
The guide, ‘Your Life, Your Choice’, offers answers to all of the possible questions a person might have when they decide to begin the journey towards Independent Living. CIL recognise that there are a large number of people with disabilities all around the country who have not yet heard of Independent Living, or who need to know more and are unsure of who to contact first.

The accompanying DVD features Barry Mooney (19) from Dublin, who lives with his parents and wants to explore independent living, and is illustrated with alternate fictional presentations of ‘Sam’ and ‘Samantha’, two people leading very different lives on the occasion of their 30th Birthday; Samantha is living independently while Sam lives at home with his parents and attends a day-care workshop.

The DVD charts Barry’s journey as he explores Independent Living.

If you would like a copy of the DVD and the accompanying information pack please contact Michael Ryan at the Blanchardstown Centre for Independent Living on: 087 237 129.

Information packs can also be downloaded from the CIL website at: www.dublincil.org/ where you can also view the DVD.
Dublin 7 Centre for Independent Living is pleased to announce the launch of a new professional advocacy service.

The service is targeted at people with disabilities who identify as being Leaders (i.e. they have an ability to lead their own lives and use a Personal Assistant (PA) Service) or who are potential Leaders and wish to explore the possibility of using a PA service and living independently.

The Dublin Leader Advocacy Service (DLAS) aims to provide focused support and representative advocacy to people seeking assistance in accessing independent living.

An advocate supports an individual to find out information (that cannot be obtained through mainstream services) and make their wishes heard. Issues which may be addressed include service provision from service providers and funders, housing, employment, education, access to health, welfare and legal supports.

Suzy Byrne is the Advocacy Officer with the DLAS and the service is now available to all Leaders and potential leaders, irrespective of where they source their PA service and the geographic area covered is Dublin city and county. The service is strictly confidential and available free of charge.

It is not an emergency service or intended as a permanent source of advocacy for an individual.

The Dublin Leader Advocacy Service is funded by Comhairle through their Community and Voluntary Sector disability advocacy programme.

The service can be contacted as follows:

Dublin Leader Advocacy Service,
21 Hill Street
Dublin 1
Telephone: 01 8726843
Email: dlas@eircom.net

Definition of “Independent Living”

The right of all persons regardless of age, type or extent of disability to live in the community, with all of the privileges that this entails – with full access to employment, transport, education, housing, health services and an active social life.
More Awareness Day Photographs

MDI Members & Fair City Cast Members in the Bistro! But who do you know (or recognise)?

Raining Chocolates!
On: Joe Mooney, Director
MDI; Martin King, TV3
Weatherman & Steven Valentine, Fundraising Officer MDI

Soaked by MDI chocolates, Martin King says it all with a smile!
A Note of Thanks!

Hi, my name is Sammy Brill. I am 28 years old and I am the Secretary on the Executive Committee for Muscular Dystrophy Ireland.

I just wanted to write a little note to say thank you to MDI for all that they have done for me, the experiences I have gained by being involved with MDI, and the friends I have as a result of becoming a member.

I am very proud to be associated with such a great organisation and I would like to offer any help or support to fellow members as has been offered to me.

If anyone needs any information, advice, a visit, or just someone to talk to, etc. please feel free to contact me. My phone number is: 086 3404516. I will try my best to help.

Best wishes.

Sammy
Flora Women’s Mini Marathon

Be part of the MDI Team

Bank Holiday Monday

4th June 2007

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 Muscular Dystrophy Ireland

We will be meeting in Café en Seine on Dawson Street after the event for a drink. For further information, sponsorship cards and T-Shirts, contact the MDI office on 1800 245300 or E-mail info@mdi.ie

Your support would be much appreciated