



# MDI News Update



*Two monthly newsletter - Issue 10, March 2003*

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## Editorial

Hi Folks,

Welcome to the latest edition of the MDI News Update. Since our last newsletter we have been very busy with our Awareness Campaign for 2003, which primarily centred around Newspaper, TV & Radio features, the selling of heart-shaped chocolates on Valentine's Day and our concert on 8<sup>th</sup> March, to celebrate the success of our Awareness activities for this year. Thanks to everyone who participated in the various media activities around the country and to people who sold chocolates and helped make this year's Campaign a great success. Once all money has been lodged, we can tell you the amount raised. (see page 4 for more).

Included in this issue is an article on FSH muscular dystrophy which outlines steps in the understanding of FSH and research developments in this area (see page 2). There is also an update on recent advances in genetic testing which many of you may find interesting (see page 3).

Do you have difficulty getting insurance, be it mortgage protection, car insurance etc? If you have been affected in any way by this issue we would like to hear from you. See page 5 for more.

On Tuesday 18<sup>th</sup> February 2003 a group of five members and their helpers went to see Manchester United play Juventus in Old Trafford. The tickets were kindly donated by Manchester United football club. A great time was had by all. For full report see page 8.

Young members, get your thinking caps on as we have also included in this issue for the first time, two quizzes, one for under 13's and one for under 18's. Fabulous prizes to be won. For more details see page 10.

Also on page 10, we introduce you to the new Youth/Respite Worker for the West, Joanne Cleary.

Are you planning on participating in the Ladies Mini-Marathon this year. If so, how about doing it for MDI? More on page 10 also.

Along with other snippets of information, there should be something to interest everyone. As always, if you have anything that you would like to see included in the future issues, do send it into us. We are always looking for news, reviews, up-coming events, photos, etc. Remember, this is your newsletter - we'd love to hear from you.

Until next time, enjoy.

**Hubert McCormack**  
Editor



*Pictured at a photo shoot to launch MDI's Awareness Campaign for 2003 are Fair City's Robin (Orla Rafter) and Jimmv (David Mitchell).*



## **Research Update 4** **Facioscapulohumeral** **Muscular Dystrophy**

Facioscapulohumeral muscular dystrophy (FSH) is the third most common type of muscular dystrophy. The name describes the usual distribution of weakened muscles: 'facio'=facial; 'scapulo'=shoulder blade; 'humeral'=upper arm. Landouzy-Dejerine and facioscapulooperoneal muscular dystrophy are two previously used terms. Also, some people with a diagnosis of scapulohumeral or scapulooperoneal syndromes may have this condition. However, the legs can also be affected.

By 1992, the cause of FSH was traced to a deletion in the region of chromosome 4, called D4Z4, which is made up of repeating units of DNA. This could be compared to reducing the number of carriages of a train. Individuals with FSH have 1-10 copies of the repeating units, whereas unaffected individuals usually have 11-150. Scientists had thought that they would find one or a few defective genes within D4Z4, like in Duchenne muscular dystrophy where the mutation is found in the dystrophin gene. However, the answer wasn't so simple.

It was only in August 2002 that an Italian scientist, Rosemary Tupler and her team, found the answer. The area D4Z4 is designed to repress the activity of genes close to it. When it is reduced, as in FSH, these nearby genes get switched on when they should be turned off, so they are more active than normal.

A potential treatment would be to block these overactive genes and this is what future research will look into.

Another breakthrough came in October 2002 when a team from Leiden University in the Netherlands published an article indicating the presence of two normal genetic variants near the D4Z4 region on chromosome 4. These variants (or alleles) are known as 4qA and 4qB. The researchers found that out of 80 people with FSH, the D4Z4 deletion always occurred in association with the 4qA variant. In these individuals' parents and in 80 people without FSH, 4qA and 4qB occurred almost equally. This suggests that either unique characteristics of 4qA cause or help the genes that are normally switched off to turn on, or that those of 4qB protect against it.

The team from the Netherlands is now looking at the differences between 4qA and 4qB to gain insights into potential therapies.

These are major steps in the understanding of FSH and the search to find a cure. Although it will take some time, the news that \$1.1 million was awarded to six laboratories in the USA and the Netherlands to conduct research into FSH in December 2000 means that there may well be more new developments to look forward to.

***Karen Jameison***  
***Information Officer***

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*If you would like any further information about FSH research, please contact Karen at 01-8721501 or email [karen@mdi.ie](mailto:karen@mdi.ie)*

*You can also find information on the American Muscular Dystrophy Association website: [www.mdausa.org](http://www.mdausa.org)*



## Genetic Testing Update

### Myotonic Dystrophy Type 2

In the last issue of the MDI News Update I had an article about research into myotonic dystrophy (DM). Since then, there has been a development in genetic testing.

Although there has been a test for DM type 1, there was no genetic test available for the rarer DM type 2. However, in February 2003, scientists at the University of Minnesota, USA, announced that they have developed the first accurate genetic test for DM2. It is thought that this will lead to better and faster diagnosis of DM2. Initial results show that DM2 is more common than previously thought, and could occur as frequently as DM1 in some populations.

Although it will take some time for this test to become available in testing centres worldwide, this is a breakthrough for people with DM2.

### Duchenne Muscular Dystrophy

Although testing is currently available for DMD, most tests only detect the absence of fairly large pieces of the gene ("deletion analysis" testing) but this mutation only applies to about 60% of people with DMD. Two American institutions are now involved in developing new tests that can detect a higher percentage of dystrophin mutations.

Scientists at the University of Utah, USA, have developed a test that they claim detects DMD at a higher success rate than the current tests and at a lower cost. The new test also detects mutations responsible for Becker MD.

University researchers will publish their findings both online and in the April print copy of the American Journal of Human Genetics.

Scientists at Baylor College of Medicine in Houston, USA, are also working on a new test for DMD, which they hope will also detect a much higher percentage of dystrophin mutations than current tests. Trials with this test are starting in America at the minute so I will keep you up to date with any developments.

**Karen Jameison**  
Information Officer

For further information, contact Karen at 01-8721501 or email [karen@mdi.ie](mailto:karen@mdi.ie) or check the news section on the MDA USA website - [www.mdausa.org](http://www.mdausa.org)

## Wordsearch

The following is a word search which was devised by Karen our Information Officer, which is a novel way for our members to become more familiar with MD related terms. Words can be in any direction. Have fun!

H	N	A	T	R	T	M	C	U
Y	M	S	G	C	S	U	F	A
H	E	S	D	E	Y	S	L	N
T	E	N	N	E	H	C	U	D
A	C	E	N	R	P	L	Y	B
P	G	A	B	E	O	E	R	M
O	C	U	L	A	R	T	E	I
Y	L	L	E	C	T	V	M	L
M	Y	L	I	M	A	F	E	K

- |          |         |          |
|----------|---------|----------|
| GENES ✓  | ATROPHY | EMERY    |
| FSH      | CMT     | MYOPATHY |
| NERVE    | TEST    | DNA      |
| HMSN     | OCULAR  | FAMILY   |
| DUCHENNE | LIMB    | MUSCLE   |
| CELL     |         |          |



# MDI News Update



Two monthly newsletter - Issue 10, March 2003

## MDI Awareness Campaign & Concert 2003

As you are all aware, this year was MDI's second National Awareness Campaign, which once again focused on the sale of heart shaped chocolates on Valentine's weekend. This campaign was a great success however, with the money from the proceeds of chocolates still coming in, it will be a few weeks before we know exactly how much we raised. We will keep you informed. We would ask anyone who has yet to return money from the sale of chocolates, to do so as soon as possible.

We would like to thank everyone who sold chocolates and supported our 2003 campaign. **A special word of thanks to: Nightline Couriers (Portlaoise), Roches Stores, Superquinn, Future Print, the cast of Fair City and all our branches and branch members for their continued support.** Your support is very much appreciated and has helped raise the profile of MDI and create a greater awareness of the condition muscular dystrophy.



MDI Members Ann Love & Peadar pictured in Letterkenny Co. Donegal selling chocolates on Valentine's Day.

To mark the close of our main awareness raising activities for this year, MDI organised a celebration concert which was held in The Johnstown House Hotel on Saturday 8<sup>th</sup> March. The concert kicked off at around 9.00pm (ish!) with MDI member Pdraig Dunne and his band who provided an eclectic mix of popular songs in a very powerful and energetic way. Pdraig, informed us on stage that he actually beat "You're a Star" runner-up, Simon Caaey in a talent competition some years ago, and I can see why - he was excellent.



Delores Crummy and Fintan Flannery selling chocolates in Sliam

Next up was "Sentimental Journey" who changed the tempo slightly, to a more jazzy and sometimes mellow setting performing some classics such as "Summertime", "Moon River" and "Fly Me to the Moon". Again a great variety of jazz and contemporary music and a great performance. "Yours truly", (myself) sang a couple of my own songs while Sentimental Journey took a short break - and that's all I'll say about that!!!!!!!

The Highlight of the night was when Café Orchestra came on stage, which was after 12.00am (unfortunately a bit late for some, who had to leave beforehand). Nonetheless they certainly got everyone on to the dance floor, with their exotic delights of Far Eastern, South American and Irish music (with the help of MDI member and host for the night, Brendan McElligott and his Russian dancing!!).



MDI Fundraising Officer, Steven Valentine pictured during our Awareness Campaign.

Nearly 200 people attended on the night, and we hope you all enjoyed the night. Thanks to everyone for your support and making the night a good success.

Hubert McCormack



## Do you have problems with Insurance

- Do you have insurance?
- Maybe you cannot get insurance?
- Maybe you can get insurance but because you have a disability you have been loaded?

If the above sounds familiar to you, you may be interested in this.

Trying to get insurance can be a major area of difficulty for people with disabilities. Here are a number of situations that have happened to MDI members recently:

'Myself and my wife were in the process of upgrading our home, the mortgage was approved, but we could not go ahead because we could not get mortgage protection. Two of the largest insurance brokers in Ireland refused cover'.

'Another member rang me in relation to car insurance. Her insurance was doubled because she had purchased an adapted vehicle'.

I am sure that there are many other members that have been put in similar positions. MDI would like to highlight this area and start a campaign to get equal status for everyone.

If you have been affected in any way by this issue, please contact us and perhaps we may be able to look at ways to address and perhaps alleviate some of these problems.

I would be interested in hearing your experiences.

**Joe T Mooney**  
**Director MDI**

## ACCESS & MOBILITY

### EXHIBITION 2003

*The Access & Mobility Exhibition 2003 will take place on Friday 30th and Saturday 31st May in the National Show Centre, Cloghran, Dublin.*

*Supported by disability organisations it brings together all suppliers, manufacturers and service providers of assistive technology and will be of interest to people with disabilities, their families, carers and professionals in the healthcare area.*

*With over 70 exhibitors anticipated thousands of members of the general public are expected to attend.*

**Admission is free.**

## MDI Drivers

Just a reminder to our members that MDI now employs two drivers. Mr Noel Kavanagh (Dublin), and Mr. Bobby Keating (Cork).

Noel is available to members who require transport to and from train stations etc. to any MDI events, hospital appointments or clinics in the Dublin area. And likewise, Bobby is available to members living in Cork.

If you require transport for any MDI event, phone the MDI office on freephone: 1800 245300.



## **Discounts for Drivers/Passengers with a Disability**

*The following is a range of discounts and tailored services in Ireland which are available to drivers with disabilities:*

### **West Link Toll Bridge, Dublin**

Drivers who have qualified for the VRT/VAT concessions by the Revenue Commissioners are allowed free access through the West-Link Toll Bridge. Application forms are available from Irish Wheelchair Association's (IWA) National Mobility Centre, Clane, Co. Kildare, and from Concessionary Travel Section, West-Link Toll Plaza, Castleknock, Dublin 15, Tel: 01 8202000. The application form must be accompanied by a passport sized photograph and proof of exemption from VAT/VRT.

### **East Link Toll Bridge, Dublin**

No application form is required in this case. In order to avail of free access, you must produce a current parking permit. To contact the East Link Toll Bridge ring: 01 6682888

### **Ferries**

The ferry operators below provide a discount to IWA members. On request, the IWA will issue a letter on your behalf confirming your membership.

- Brittany Ferries Tel: 021 4277801 – Cork to Roscoff
- Irish Ferries Tel: 01 6610511 (formerly B&I) Rosslare to Pembroke, Dublin Port to Holyhead, Rosslare to Cherbourg, Rosslare to Roscoff.
- Stena Tel: 01 2047700 – Dunlaoghaire to Holyhead, Dublin Port to Holyhead, Rosslare to Fishguard.
- Swansea Tel: 021 4271166 – Ringaskiddy to Swansea.

## **Fleet Discount for Vehicle Purchase**

Below is a list of car distributors who offer a discount to IWA members purchasing a new vehicle. As the discounts are varied, it is advised that you contact the National Mobility Centre, for more details.

*Citroen, Hyundai, Opel, Subaru, Daewoo, Mitsubishi, Peugeot, Toyota, Fiat, Mazda, Renault, Volkswagen, Ford, Nissan, Seat.*

## **Hire of vehicles**

If you wish to hire an automatic vehicle with hand controls you can do so by contacting the following:

- John O'Meara 0902 92325
- Hertz Car Rentals 053 52500

## **Motor rescue**

Cuchulainn Motor Rescue is now offering a rescue service designed to meet the needs of the physically disabled motorist. The service provides a comprehensive back-up in terms of accessible taxis, accommodation and driving adaptation companies. For further details please contact 1850 247911.

**For more information about any of the discounts or services listed above contact:**

**National Mobility Centre,  
Ballinagappa road,  
Clane,  
Co. Kildare**

**Tel: 045 893094  
Email: [maats@iwa.ie](mailto:maats@iwa.ie)**



## CMT / HMSN Support Group

CMT United Kingdom is a national support group in the UK for people affected by Charcot-Marie-Tooth Disease, also known as Hereditary Motor and Sensory Neuropathy (HMSN) or Peroneal Muscular Atrophy.

I recently received information from Karen Butcher, Secretary of CMT UK, and she informed me that they would like to extend their services to people with the condition in Ireland. There are already around 20 people in Ireland on the CMT UK mailing list, and if anyone else would like to join, there are contact details at the end of this article.

CMT UK has various pieces of literature available, including "What is Charcot-Marie-Tooth Disease?", "Living with Charcot-Marie-Tooth Disease" and "A Simple Guide to Charcot-Marie-Tooth Disease" (a leaflet about the condition for children). There is also a newsletter, "ComMenT" that is published four times a year. It is filled with articles about CMT, aids and appliances, holidays, and much more, with a lot of general interest articles written by members. For example, in the winter 2002 edition, there were articles about working from home, orthotics, travel, physiotherapy and individual experiences with a fight to get a parking badge and problems with doctors who were not aware of issues affecting people with CMT. There is also an article called Medical Question Time, where members can submit questions about CMT to be answered by doctors (although if someone has concerns about a personal medical issue it is still important to consult your own doctor).

The main benefits come from members sharing information and experiences.

*If anyone would like to join CMT UK or would like more information about them, I have some membership forms and a couple of copies of their literature in the Dublin office, or you can contact them directly at:*

*CMT United Kingdom, PO Box 5089, Christchurch, BH23 2WJ, UK.*

*Email Karen Butcher at: [secretary@cmt.org.uk](mailto:secretary@cmt.org.uk)*

*Website: [www.cmt.org.uk](http://www.cmt.org.uk)*

**Karen Jameison**  
Information Officer

## Benefit Night

Supporting  
**Muscular Dystrophy Ireland**

### Easter Sunday

20<sup>th</sup> April 2003

**Venue: Rathvilley Inn**  
**Co. Carlow**

**Time: 9.00pm**

*Music by:*

**The Pub Crawlers**

**Tickets (at the door):**

**€5.00**

**All Welcome**

## Make Friends Across the World



Alexander Mitskovich is a 23 year old man from Belarus who has an unspecified type of muscular dystrophy. He would love to hear from people in Ireland and his English is quite good, so if you would like to contact him, his details are:

Alexander Mitskovich, Suvorov Street,  
96-28, Brest, Republic of Belarus

Email: [sasha-m2002@tyt.by](mailto:sasha-m2002@tyt.by)

## MDI YOUTH PAGE

### National Youth Activities

February was a busy month for MDI. With our awareness day but we still managed to squeeze in a trip to see Manchester United win in Old Trafford against Juventus. The lucky members that got to go were Ed O'Connell (Cork), Michael McDonald (Kilkenny), David Cunningham (Leitrim), Wesley Kavanagh (Dublin) & Colm Cusack (Roscommon).

The excited and enthusiastic fans travelled over by Ulysses on Tuesday morning 18<sup>th</sup> February 2003. We stayed the night just 25 minutes away from Old Trafford. After arriving that evening we had dinner but couldn't get it fast enough because we wanted to go off and watch Arsenal play their match.



*"On display!"*

*Pictured amongst the trophies on display at the Old Trafford Museum in Manchester are MDI members Wesley Kavanagh, Dublin; Colm Cusack Roscommon; and Ed O'Connell Cork*

The day of the match was packed full of things to do. We headed off to what seemed to be the largest fully accessible shopping centre we had ever seen, "The Trafford Centre." There were well over 100 shops, plenty of restaurants, cinema screens and bowling lanes. It was an eye opener.

After all the shopping we headed over to Old Trafford, some of the group with eyes wide open and jaws dropped, as we pulled up outside!!! It was only 4pm and already the atmosphere was building. We went in to the Museum to have a few photos taken with the UEFA cup and all the other trophies United have won over the years!!



*"Like Father, Like Son!"*

*Michael McDonald (Jnr) enjoying the match with his Dad, Michael McDonald (Snr), pictured on the sideline at Old Trafford, Manchester.*

The crowd was building outside and the atmosphere was growing twice as much. A quick trip around the Superstore was next. Finally the long awaited entrance into the Old Trafford stadium. The group was overwhelmed with the size and the electric buzz around the stadium. The end result was a win for United. A very happy and content group left Old Trafford that night with smiles on some faces that you just could not wipe off (even Noel tried!) and a memory that would last forever.

*A Huge Thank You to Manchester United, Irish Ferries, Old Trafford Museum (Stephanie & Matthew), Irish Association for Spina Bifida & Hydrocephalus & to Noel (our bus driver & Liverpool Supporter!)*

**Noeleen Fagan  
Youth Worker - MDI**

## MIDI YOUTH PAGE (Contd.)

### Dublin Youth Club

#### February 03

February saw two trips to the Coca-Cola Factory by our Youth Club. One on Monday 17<sup>th</sup> and the second on Monday 24<sup>th</sup> February 2003. The groups went along to the factory on the Naas Road, and met with Tom, our tour guide for the morning. Tom took us through the history of Coca-Cola and brought us to meet Dixie (the oldest Coca-Cola machine in Ireland).



*"Cool Cola Cap!!!!"*

Pictured wearing his coca-cola hygiene hat while on tour of the Coca-cola Factory is MDI member Seamus Fagan, Dublin.

We were taken on a tour around the inside of the factory and then headed back to the meeting room to answer some questions. Whoever answered a question right got a can of coke. Everyone received a free pencil case and poster when leaving the factory. Both groups had a fantastic time and really enjoyed their tour.

### The Foroige Club

The next Foroige Club meeting will be held on Saturday 5<sup>th</sup> April 2003. Details will be sent to those involved in due course.

*Noeleen Fagan  
Youth Worker - MDI*

### New Youth/Respite Worker in the West

Hi everyone,

My name is Joanne Cleary, and I have in the past few weeks joined MDI as a Youth/Respite Worker in the Western region covering the counties of Galway, Roscommon and Mayo. I have just moved from my home in Wexford to Galway city and I am getting to know my way around slowly but surely!



*Joanne Cleary*

I hold a National Diploma in Applied Social Studies & Social Care, and have worked in various settings. Working with MDI will be a slightly new direction for me, and one which I look forward to. I have met some people, but still have a lot of faces to put to a lot of names. So if you hear of a very lost looking person rambling the roads of the west, it could well be yours truly!

**You can contact Joanne in our Galway office on 091 563000 or on her mobile: 086 3899286**

### New Galway Office

MDI have a new Galway office, the address is: **Unit 15a, Ruston House, Dominick Street, Galway. Tel: 091 563000.**

## MDI Bumper Quiz Challenge

Pit your wits against  
the MDI Super-  
Computer!



Below are two quizzes, one for under 13's and one for teenagers (under 18's). There are fabulous prizes to be won.

### QUIZ FOR UNDER 13's

#### Prizes for 8-13 years quiz

- 1<sup>st</sup> F-14 Tomcat Plane
- 2<sup>nd</sup> Helicopter
- 3<sup>rd</sup> Robot Combatant

(All the above toys are remote controlled)

- Q.1 Who is the current Manager of the Irish soccer team?
- Q.2 On which date is the longest day of the year?
- Q.3 Who sings the pop song 'Skaterboy'?
- Q.4 In which country was the Pope born?
- Q.5 Who are the current All-Ireland Football champions?
- Q.6 In which movie would you find the character Peter Parker?
- Q.7 Which band headlines Slane this year?
- Q.8 The actor Tom Cruise has a disability. What is it?
- Q.9 Which famous German composer was deaf?
- Q.10 In which film does Jennifer Lopez play a hotel worker?

### QUIZ FOR 13-18 YEAR OLD's

#### Prizes for 13-18 year quiz

- 1<sup>st</sup> Choice of a pair of tickets to see either Robbie Williams, Westlife or Bon Jovi
- 2<sup>nd</sup> Next choice of the above tickets!
- 3<sup>rd</sup> Last choice of above tickets!

- Q.1 Who currently wears the number 1 jersey on the Irish rugby team?
- Q.2 Who scored the two goals when Ireland beat Scotland in soccer recently in a friendly?
- Q.3 Which artist recently won eight Grammy awards?
- Q.4 From which town in Donegal is You're a Star winner Mickey Harte

- Q.5 In which US state was George Bush Governor before becoming President?
- Q.6 Which Irish actor was said to have recently gone out with Britney Spears?
- Q.7 In what year was MDI founded?
- Q.8 What is the name of the progressive condition that actor Michael J. Fox has?
- Q.9 What is the correct term for the new Dublin Spire?
- Q.10 Who won the first Grand Prix of the current season at Melbourne?

**Please note** that once all correct entries are received a draw will take place for the prizes. The decision of the judges is final. All entries should be received by 10<sup>th</sup> April 2003.

Write your answers (clearly numbered) on a sheet of paper along with your name, address and date of birth and return to Noeleen Fagan, MDI, Coleraine House, Coleraine Street, Dublin 7




## Bank Holiday Monday 2<sup>nd</sup> June 2003

MDI are looking for runners & walkers (female and male!!!) to participate in this years Women's Mini Marathon. T-shirts and sponsorship cards will be provided.

All runners are invited back to the Mansion House on Dawson Street afterwards for a post marathon *warm down* and reception where refreshments will be served and you will have an opportunity to meet fellow runners and members.

All runners are advised to register for this event directly, details for which can be found in the Evening Herald every Thursday and Saturday until 26<sup>th</sup> April 2003.

Get your entry form in to the Evening Herald before **1st April** to be included in a draw for a **Sunway Holiday**, a **Ryan Hotel Weekend** or one of twenty **Nike rucksacks**.

All entries must be on an Official Entry Form. Closing Date: Wednesday 30th April 2003.

For T-shirts and sponsorship cards contact Steven on freephone 1800 245300



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Membership subscriptions for 2003 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



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