

# **Muscular Dystrophy Ireland**

## **Annual Report 2006**

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Company registered name: Muscular Dystrophy Ireland Ltd.

Company registered office: 71/72 North Brunswick Street, Dublin 7

Country of registration: Ireland - 60460

Directors: Florence Dougall, Jimmy Murray, Sammy Brill, Joe Jameson, Ed Jameson, Elaine McElliott, Hennie Walsh

## **Muscular Dystrophy**

Muscular dystrophy is the collective name for a range of neuromuscular conditions, which are characterized by the progressive weakening and wasting of the muscles. It can affect adults and children. Some forms arise at birth or in childhood, others may not manifest themselves until later in life. Each type of muscular dystrophy arises from a different genetic mutation or deletion which is inherited from one or both parents, or is due to a spontaneous mutation. This means that there are many families who have more than one member with the condition.

There is no cure for muscular dystrophy but there have been huge advances in increasing the quality of life for people with the condition and scientists around the world are working hard to develop new treatments.

## **Muscular Dystrophy Ireland**

Muscular Dystrophy Ireland (MDI) is a voluntary organization, which was established in 1972 by a small group of people in the west of Ireland to support families who had a member with muscular dystrophy. Since then it has grown considerably and it now has a membership of over 500 members and a network of branches throughout Ireland. There are now MDI offices in Dublin, Cork, Galway, Sligo, Tullamore and Kells, and MDI staff members are also based in the Mid-West and South East regions. MDI's primary objective is to provide support for people and their families who are affected by muscular dystrophy and allied neuromuscular conditions.

**In 2007, MDI will celebrate 35 years of providing support to people with muscular dystrophy and their families.**

### **Mission Statement:**

Muscular Dystrophy Ireland aims to provide information, advice and support to people with neuromuscular conditions and their families through a range of support services. Our objective is to promote through practical empowerment, independent living for people with the condition muscular dystrophy. MDI supports lobbying for a change in policy and services to enable people with neuromuscular conditions to fully participate in society and to live a life of their own choosing. MDI also aims to support and fund research into neuromuscular conditions.

## **A Message from the Director**

Hi,

This has been another very busy and exciting year for MDI. Over the past twelve months MDI has endeavoured to increase our Family Support and Youth Respite Services nationwide. To increase these supports and services takes financial support, so I would like to take this opportunity to thank the Health Service Executive areas and all MDI members and friends for their fundraising support throughout the year. These increases in supports and services are outlined in this report.

2006 has proved to be a very exciting year in research. MDI joined the Medical Research Charities Group and was pleased to be among the recipients of research grants from the MRCG / Health Research Board joint funding scheme. MDI is now funding two research projects, one with Prof. Kay Ohlendieck in NUI Maynooth, and the other with the MDEX Consortium in the UK, who are looking at exon skipping as a potential therapy for boys with Duchenne muscular dystrophy. This is an exciting time for research and MDI is very pleased to be involved.

I would like to thank Ms. Florence Dougall, National Chairperson, and the National Executive and Council for their support and encouragement. I would also like to thank all the staff for their hard and dedicated work over the past twelve months.

I am looking forward to the challenges that 2007 brings and will strive to enhance the supports and services that our members require. If any member would like to contact me please feel free to do so.

Regards,  
Joe T Mooney,  
Director MDI

## **Chairperson's Report**

The year 2006 saw Muscular Dystrophy Ireland continue to progress and enhance services for our members.

January saw the momentous occasion of the official opening of our offices, in North Brunswick Street, Dublin 7. This was officiated by Ms Mary Harney, Minister for Health and Children.

With February came MDI's 5<sup>th</sup> Annual Awareness Day on St. Valentine's Day. A huge amount of effort went into this event to ensure its success and I would like to thank all who helped out before, during and afterwards for their help. Prior to our AGM held in May, Prof. Kate Bushy gave a presentation on the exon skipping research project (see research update).

Four summer camps took place during the year. The camps are a key respite service provided for members by MDI, and are much enjoyed by all who attend. During May and June and after lengthy debate, Respite Guidelines were drawn up and approved by National Council. The guidelines aim to provide transparency and accountability of the respite services offered to members.

In June a number of our staff members attended the Harley Davidson European Rally in Killarney where funds were raised and awareness was spread. Raising awareness of muscular dystrophy through fundraising remains a key aim of the Organisation and Branches. MDI plan to continue to raise awareness and raise funds in 2007 as we prepare for the new Charities Legislation Bill, which will require strict accountability on how voluntary organisations, and their branches raise and spend funds.

In September the Members' Guide to MDI was launched, the aim of which is to inform members and professionals of the services provided by MDI and how to access them. In October, MDI made a presentation to the Joint Oireachtas Committee on Health and Children (see report inside). In December a Memorial service was held in Cork to commemorate deceased past members in that region. This service was very well received and MDI intend to hold similar services in other regions in 2007.

The administration of the Organisation continues to face challenges as demands from external sources are met, both legislative and regulatory. MDI has been working diligently to meet these demands over the last number of years. The Organisation has been concentrating on developing organisational policies and procedures to support staff and ultimately improve the services to members.

2006 also saw the commencement of a Health and Safety project within MDI. Health and Safety is a major and necessary undertaking for MDI and I'm glad

to report that it is well on the way to meeting the legislative requirements. The success of Health and Safety is very much down to the collaborative work of staff and the continuing work of the Health and Safety Committee.

During 2006 the decision was taken by the National Council and Executive to review the Organisation's Memo and Articles. It was a timely decision as the Organisation is now over 34 years young, growing and developing in a very different environment to when the vision of MDI took flight. As mentioned above the Organisation is facing, as are all voluntary organisations, increasing legislative and regulatory requirements which have a major impact on the governance of the Organisation. To address this, National Executive and Council members will undergo training in Management Committee Skills following their election to their new positions. Further supports will be developed to support the dedicated work of our volunteer committee members.

In 2006 we recruited four new staff members, Fiona O'Donoghue Administrator and Lisa Fenwick FSW, Stephanie Fagan and Ciara Kelly, YRWs, who joined the Organisation to cover maternity and other leave. We sadly lost Noel Kavanagh our driver in the eastern region who passed away in June. He is fondly remembered and missed in the Organisation.

At this stage I'd like to take the opportunity to thank all members of the National Council and Executive Committees for their dedication to the work of MDI. I'd like to mention Ursula Hagerty who passed away in March 2006. Ursula was a dedicated committee member of MDI and a long-time friend of the Organisation. She is sadly missed.

I would also like to thank the Department of Justice, Equality and Law for their once off Independent Living Grant.

MDI plan to continue to develop and improve the services and supports offered to members. The development of a Strategic Plan to guide the work of the Organisation over 5 years is in the planning for 2007. It is an exciting time for MDI as it continues to grow and to develop. The good work of MDI is due to the dedication and commitment of members, board members, staff, volunteers and friends, thank you all and long may it continue.

On behalf of MDI and its members I would like to extend a word of thanks to all the Health Service Executives for their financial support throughout the year and over the past number of years; to Dr. Brian Lynch and his team at the Central Remedial Clinic, and Dr. Orla Hardiman and also Prof. Richard Costello and their teams at Beaumont Hospital for their continued support of MDI's objectives.

Thanks also to the local branches, sub-committees, National Council and National Executive for their work during this last year. I would like to sincerely thank the director and staff for their continued commitment to MDI; I would like to thank all our funders, fundraisers and members who make the work of MDI possible.

During 2006 MDI has lost a number of members and I would like to extend my deepest sympathy to all the families and friends of these members. May they rest in peace.

Finally, I would like to emphasize MDI's commitment to its members and their families; MDI will continue to support them in every possible way.

Let us all as members keep doing what we are doing but always strive to do it better for all.

Regards,  
Florence Dougall  
National Chairperson

## MDI Network of Support

### New Head Office

2006 got off to a good start for MDI, as Ms. Mary Harney TD, Minister for Health and Children, then Tánaiste, officially opened MDI's Head Office in Dublin. Having been a part of the Carmichael Centre for Voluntary Groups since its formation in 1988, moving into a stand alone office in Dublin was a big step for MDI and a mark of its achievement and growth in recent years.

MDI's management and administration teams are based in this Head Office, along with national services including information, research and fundraising. Members of MDI are welcome to use its facilities, including a meeting room and computer access.



### Photo Details

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

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

Bottom left: An Tánaiste and MDI Chairperson address the gathering.

Bottom right: Ms. Mary Harney T.D. unveils the plaque.

## **Regional Offices**

MDI has five regional offices, in Cork, Galway, Sligo, Tullamore and Kells, Co. Meath. There are also MDI staff members based in the mid-west and south-eastern regions. Family support is available throughout all HSE regions of Ireland, while Youth / Respite Workers are based in the east, south, west, midlands and north east.

## **Branches**

There are 8 active Branches associated with MDI: the South East, Donegal, Kerry, Cork, Mountbellew in Galway, Midlands, Dublin and the North East Branches. They are coordinated by volunteers – people with muscular dystrophy, their families and friends.

Local branches take part in various activities, which can include:

- Fundraising.
- Informing people about muscular dystrophy and the activities of MDI.
- Informally supporting members locally.
- Operating as a forum for local members to meet.
- Offering peer support to members newly diagnosed with muscular dystrophy.
- Putting forward ideas concerning the ways in which MDI should move forward.
- Designating representatives to local statutory agencies on behalf of MDI, for example, Health Boards.
- Participating in and supporting MDI national events, for example, Awareness Day, national fundraising etc.

## **Muscular Dystrophy Ireland has:**

- **469 individuals with muscular dystrophy registered as members of MDI, as well as a number of bereaved families who continue to avail of support.**
- **6 offices nationwide.**
- **8 Branches.**
- **25 core staff, 14 care workers and a bank of volunteers, camp workers and PAs nationwide.**

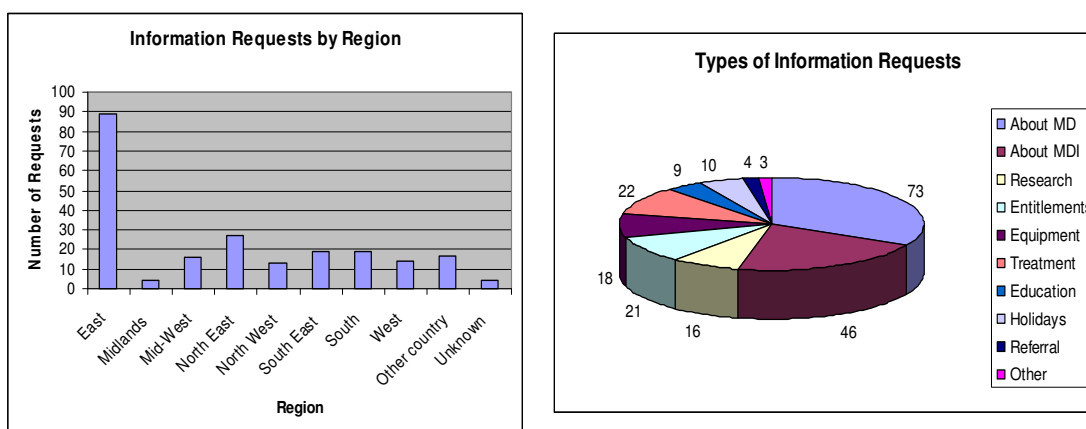


## The Information Service

MDI's Information Officer is based in the Head Office in Dublin. Queries are received by phone, email, letter and in person from people who would like information about muscular dystrophy and related issues, such as research, entitlements, accessing equipment and adaptations etc. Information requests are received from a range of people, including members and staff of MDI, people and family members newly affected by muscular dystrophy, students carrying out projects, health care professionals, teachers and special needs assistants.

In 2006, a total of 222 information requests were recorded. This is a slight increase on 2005's total of 213. Most requests came from the eastern region of the country, which would be expected with a higher population density, and the remainder were quite evenly distributed throughout the rest of Ireland, as well as some international requests.

Most requests asked for information about muscular dystrophy, including information specific to a particular type of the condition. As well as the people who requested information about research, there is always a research section in the MDI News Update to update members on developments in this area.



## Members' Guide to MDI

In September 2006, a new publication was launched. The booklet "Members' Guide to MDI" is a comprehensive overview of the structure of the organisation, detailing the supports that are provided to people with muscular dystrophy and their families. It explains the process for accessing support from MDI and highlights how people can become involved in the organisation. Thank you to Comhairle, who part-funded this publication.

Karen Pickering, Information Officer, and Joe Mooney, Director, travelled to Portlaoise, Monaghan and Macroom, Co. Cork in September and October 2006 to launch the new publication and consult members on their vision for the future development of MDI. Thank you to those who attended these information and consultation evenings.



*The new "Members' Guide to MDI"*

### **Newsletter and Website**

MDI's News Update is sent to members and friends of MDI every two months, and it is a source of information about events that MDI is organising, developments in research, updates on entitlements and reports on youth activities and regional news, to name but a few. In 2007, there will be a new development with the newsletter: it will now be printed in colour.

**752 people receive the MDI News Update every two months.**

MDI's website, [www.mdi.ie](http://www.mdi.ie) is also a source of information about the organisation and muscular dystrophy; again it is currently undergoing development and will be relaunched in 2007.

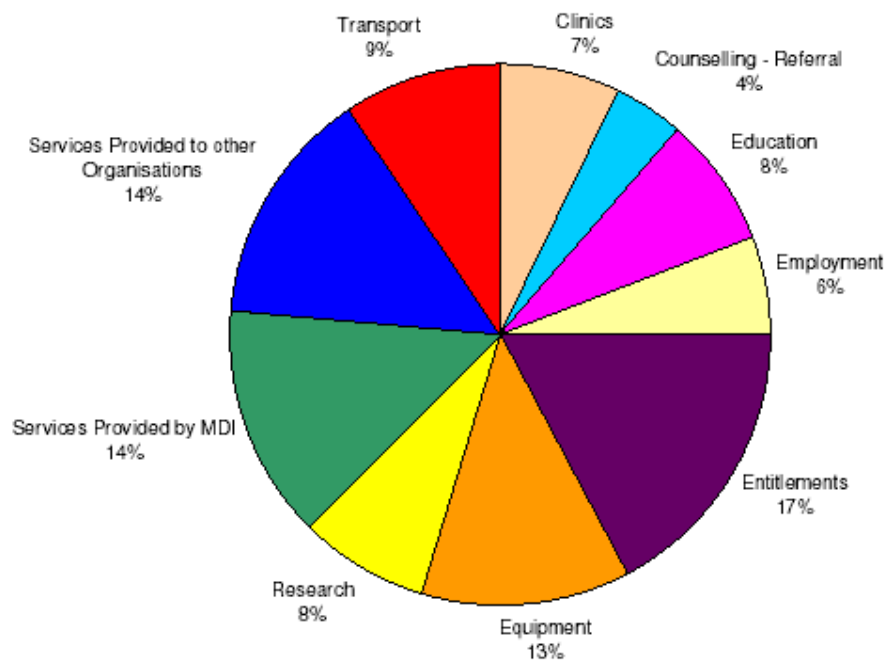
## Family Support Service

The Family Support service is an essential support that MDI provides to individuals with muscular dystrophy and their families. MDI now has a Family Support Worker (FSW) available in all HSE regions of the country. Lisa Fenwick joined the FSW team in 2006 to provide maternity cover in the west and the midlands regions.

The role of the FSW is to provide support to people with muscular dystrophy and their families. This service could be in the form of home visits, telephone contact or group meetings, depending on the needs of each person.

The chart below details the areas of support that FSWs provided during 2006. A large proportion of work is in sourcing and providing information about entitlements and equipment, as well as liaising with other agencies to access support for families.

**Support Services to Members - Family Support Workers - 2006**



*These figures are taken from the new MDI database which is still being developed. These are approximate figures and are based on the services MDI provide nationwide.*

## Respite

The respite service is an essential support for people with muscular dystrophy and their families. Services are coordinated by the Respite Coordinator, Ms. Kate Power, from Head Office in Dublin. There are currently five Youth / Respite Workers providing support to families in the east, south, midlands, west and north east regions. MDI also employs Respite Workers throughout the country, who work directly with individuals and families.

### MDI RESPITE CAMPS 2006:

Four MDI camps were held during 2006 with a total of 60 members participating.

Three camps were held in Kilcuan Lodge, Clarinbridge, Co. Galway. Members availed of the opportunity to see the magician Keith Barry in April, attend comedy nights in September and local pubs, restaurants, cinema, bowling venues. One camp was held in Share Village, Co. Fermanagh which focused on out door activities. Members participated in activities such as canoeing, go-karting, wall climbing, speed boat, archery etc.

Type of Camp:	Number of Participants:
1. April Camp (15-18 years)	16
2. July Camp (11-15 years)	22
3. September Camp (18-25 years)	10
4. October Camp (over 25s)	<u>12</u>
<b>Total:</b>	<b>60</b>



*Go-Karting at the MDI Summer Camp*



*Taking a trip in a speed boat at the MDI Summer Camp*

### **MDI YOUTH SERVICES:**

2006 was a very busy year for Youth Services with one youth worker going on maternity leave and another youth worker taking a year unpaid leave. MDI welcomed two new youth workers to the team Cíara Kelly in the south and Stephanie Fagan in the midlands, to provide cover for the staff who were on leave.

“The primary task of youth work is to offer young people, on a basis of their voluntary involvement, development and educational experiences which will equip them to play an active part in our democratic society as well as meet their own developmental needs through a challenging programme of social education which assists the young person to be an active and critical participant in society and social development” (National Youth Federation, 2001).

The aims of the MDI Youth Work Programme are as follows:

- To empower our young members
- To encourage meaningful participation
- To provide an educational aspect
- To promote equality of opportunity

MDI Youth Respite Workers provide respite under the following areas:

**Social / Recreational:**

Lunch  
Cinema  
Bowling  
Theatre  
Circus  
Concerts  
Play Station Tournaments  
Teen Discos  
Shopping Centres  
Beauticians  
Dinner  
Parties  
Kids Fun Centres  
Home Visits

**Educational:**

Art Workshops  
Crafts Workshops  
Music Workshops  
Film Making Workshops  
Computers  
Museums  
Drama Workshops  
Leisure Plex  
Zoo  
Army Barracks  
Parks & Gardens  
Fota Island  
Historical Trips e.g. New Grange Farm

**Sport:**

Power Soccer  
Swimming  
Mondello Race Track  
Ice Skating  
Horse Riding  
Boccia  
Pool Workshops  
Canoeing  
Banana Boats  
Wall Climbing  
Orienteering  
Go-Karting

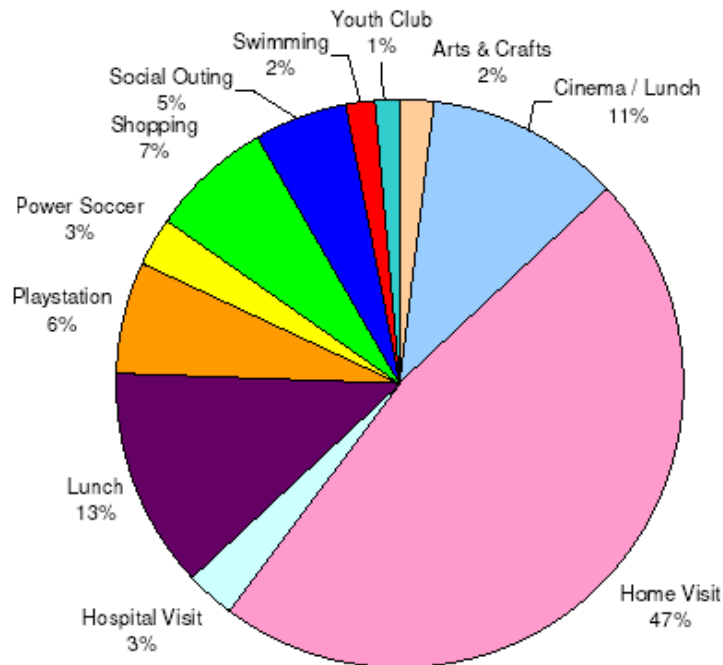


*Power Soccer in action!*

The chart below shows the types of support that Youth / Respite Workers provided to young members with muscular dystrophy and their families during 2006. A large proportion of the YRWs time is spent on home visits, when they visit a young member in their own homes, enabling their parents or carers to have a break.



### Youth Services to Members - 2006



*These figures are taken from the new MDI database which is still being developed. These are approximate figures and are based on the services MDI provide nationwide.*

### RESPIRE SERVICES:

MDI provides PA respite services only when all other PA service providers have been exhausted e.g. IWA, CIL, Home Help Service, Health Service Executive etc. During 2006 MDI supported 18 families nationwide by employing PA's to support the member and family. In addition MDI also supported respite breaks for members and families by providing PA cover during nights out and weekend breaks.

## **Clinics**

Muscle clinics for people with muscular dystrophy continue to run successfully in two locations. The children's clinic takes place in the Central Remedial Clinic in Dublin, and is run by Dr. Bryan Lynch, Paediatric Neurologist. Children who attend also have access to support services including a dietician, physiotherapist, occupational therapist and psychologist. This clinic runs every second Monday in the CRC. The adults' clinic is run by Dr. Orla Hardiman, Consultant Neurologist, in Beaumont Hospital, Dublin, and takes place on the last Thursday of each month.

MDI's Family Support and Clinic Coordinator, Margaret Goode, is available at these clinics to support the individuals and families who are attending.

In 2006 a new clinic started up in the cardiology unit of Our Lady's Hospital for Sick Children in Crumlin, Dublin. This will enable them to monitor the heart function of children with certain types of muscular dystrophy, and enable them to begin treatment if and when it is required. This clinic takes place on the first Wednesday of each month.

Anyone wishing to attend these clinics can contact their Family Support Worker or get a referral from their GP.



## **Staff Development**

MDI strives to support and train its staff in order to ensure the highest standard of services to members. Staff joining the organisation undergo an induction programme to introduce them to their role, organisational policies and procedures, and the organisation as a whole.

Our aim is to provide manual & patient lifting training, first aid, disability awareness and care skill training to staff, working in roles which require it, within the first six months of their employment. We also provide Child First training to all of our staff members when they join. During 2006 Kate Power, Respite Co-ordinator trained as a Child First Facilitator/Trainer with the Western HSE.

With health and safety as a priority, it is MDI's policy that all staff who drive MDI vans undertake a MiDAS course (the Minibus Driver Awareness Scheme), in advance of carrying out driving duties. In 2007 we aim to train a staff member to become a MiDAS instructor, ensuring that this important training is readily available to staff and members.

In 2006, staff from the family support, youth / respite and administration areas took part in a self-care day.

MDI also participated in the Neurology Training Network in 2006. This network consists of some of the member groups from the Neurological Alliance of Ireland, including MDI, and it received funding from the Wheel to develop a training programme. MDI staff members were able to participate in a range of courses, including a management training course, media skills training, supporting support groups and a managing volunteers course. This training also provided an opportunity to forge links with people from other voluntary organisations.

Through training, staff development and support our aim is to continue to deliver the highest standard of care to our members.

## IBM Working in Partnership with MDI

### IBM – accessibilityWorks Project

As a result of a funding application to IBM in early 2006, MDI were chosen to participate in an exciting new project referred to as the **IBM accessibilityWorks Grants Project**, which commenced towards the end of the year.

The purpose of the **IBM accessibilityWorks Grants Project** is to create increased web accessibility and usability opportunities for people with disabilities, employing newly-developed applications based on Linux software.

To help achieve this goal, IBM donated five laptop computers to MDI, which all have IBM custom-built software installed on them. MDI have been requested to evaluate and provide feedback on this software. Five MDI members were identified to evaluate this software over a six month period and it is hoped that this project will ultimately enable easier and more effective web page navigation for people who have difficulty reading web pages or using the mouse or keyboard for web activities.

The IBM donation to MDI in connection with the *accessibilityWorks* project includes:

- A donation of five laptop computers, for the purpose of evaluating and providing feedback of software;
- A startup donation of €4,000 (for project expenses);
- Technical support from IBM personnel to assist with the project;
- New Linux-based accessibilityWorks and Head Tracker Pointer (HTP) software;
- Training on the use of the Head Tracker Pointer (HTP) and *accessibilityWorks* browser extensions.



*Pictured at the IBM offices in Pembroke Street, Dublin at a presentation of 5 Laptop Computers to MDI are:*

*Back row:*

*Bojan Tomic (Personal Assistant), Deirdre Kennedy (Corporate Community Relations Manager IBM), Larry Ade (Personal Assistant), Michael Daly (Country General Manager, IBM),*

*Front row:*

*Joe Mooney (Director MDI) and Hubert McCormack (Administrator MDI)*

***MDI are very excited about this new collaboration with IBM and we would like to thank IBM for choosing us to assist them in their research in helping to evaluate what promises to be a very worthwhile initiative.***

## Research

MDI aims to support and fund research, both biomedical and social. 2006 proved to be a big year for research, highlighted by MDI becoming a member of the Medical Research Charities Group (MRCG). This umbrella organisation provides support for voluntary organisations in Ireland that fund or carry out research. MDI representatives attended several training sessions organised by the MRCG in 2006, including "Science for non-scientists", "Patient Registries" and training on forming a Research Committee and analysing grant applications.

Membership of the MRCG also entitled MDI to apply for funding to carry out research under the Medical Research Charities Group / Health Research Board Joint Funding Scheme, 2006, and we were fortunate to be awarded funding for two projects. These are now being funded jointly by MDI and the MRCG / HRB scheme.

Prof. Kay Ohlendieck, Head of Biology in NUI Maynooth, was awarded funding for a three year project due to begin in March 2007, entitled "Identification of Novel Biomarkers in Dystrophic Heart and Muscle Fibres Using Comparative Proteomics".

There is a great deal of interest in the MDEX Consortium research study "Restoring Dystrophin Expression in Duchenne Muscular Dystrophy: A UK Consortium for Preclinical Optimisation and a Phase I/II Clinical Trial Using Antisense Oligonucleotides" and because of this, the consortium was awarded funding for one year.



*Mr. Joe Mooney, Director of MDI, presents a cheque to researchers from the MDEX Consortium towards their research.*

**MDI would like to thank the members who have fundraised tirelessly to raise the money to enable MDI to fund these projects.**

## MDI Visits Dáil Éireann

In August 2006, MDI received an invitation from the Chairman of the Joint Committee on Health and Children to make a presentation in relation to research advances in the potential treatment of Duchenne muscular dystrophy. This invitation arose from the interest in the UK consortium's exon skipping research.

On Thursday 26<sup>th</sup> October, a delegation from MDI arrived at Dáil Éireann to present to the committee. This delegation consisted of Mr. Joe Mooney (Director of MDI), Mrs. Karen Pickering (Information Officer), Ms. Kate Power (Respite Coordinator), Mr. Hubert McCormack (Administrator), Mr. Jimmy Mooney (MDI member) and Dr. Matthew Wood (member of the MDEX consortium, from the University of Oxford).

After an introduction from Joe Mooney, Kate Power gave an introduction to the supports that MDI provides to members. Karen Pickering informed the committee about Duchenne muscular dystrophy and the present steps to manage the condition. Dr. Wood then spoke about the status of the exon skipping research, and the need for further funding to ensure its progress.

The committee then had an opportunity to ask questions, and they demonstrated an awareness of the broad issues affecting members of MDI, such as lack of multidisciplinary neurology clinics, lengthy waiting times to see consultants, difficulties in accessing respite, Personal Assistants and accessible transport.

The meeting was very productive, giving MDI an opportunity to inform the government about muscular dystrophy, the work of MDI, and the importance of funding research into the condition and into supports for people with muscular dystrophy.



*Pictured outside Dáil Éireann are (back row) Jimmy Mooney, Kate Power, Dr. Matthew Wood and Karen Pickering; (front row) Hubert McCormack and Joe Mooney*



## Fundraising Report

MDI has three national fundraising events throughout the year, the National Awareness Day, the Flora Women's Mini Marathon and Christmas card sales. In 2006, MDI participated in two new fundraising events, the European Harley Owners' Group rally and a GAA football final tickets raffle. Members of MDI also take part in local fundraising events, such as greyhound nights and table quizzes.



*Joe Mooney, Director and Florence Dougall, Chairperson, with MDI member Eamonn Nolan, who organised a greyhound race night*



*Members from Donegal who raised funds for research.*

## National Awareness Day Campaign

MDI's fifth National Awareness Day Campaign took place on St. Valentine's Day, 14<sup>th</sup> February 2006. As part of the awareness raising activity, MDI sold two handmade heart shaped chocolates in attractive red and white boxes appropriate to Valentine's Day. The chocolates were sold in Spar shops nationwide and it was a great success. MDI would like to take this opportunity to thank our members, friends and volunteers who supported this campaign.

The proceeds from the sale of chocolates have reached to over **€66,000** in profit.



*Steven Valentine, Fundraising Officer holds a cheque from Spar, raised through the sale of MDI chocolates. Joe Mooney, Director, talks with Safann McCarthy, Spar's Marketing Manager in the background (Photo by John T. Ohle Photography).*

### **Flora Women's Mini Marathon**

This was another successful Dublin Women's Mini Marathon for MDI. A great day was had by all the members and friends of MDI who participated. This year there was over **€15,700** raised.



*Some of the MDI participants at the Flora Women's Mini Marathon, June 2006*

## Christmas Cards

Once again, as part of our annual fundraising efforts MDI sold Christmas cards nation-wide. MDI would like to thank everyone who sold or bought Christmas cards. These are available every year from MDI's Head Office.

## Harley Davidson European Rally

In June 2006, Harley-Davidson owners from all over Europe rode into Killarney for the European Harley Owners Group (HOG) Rally. Harley-Davidson bikers exhibited their bikes, partied and paraded through the ring of Kerry in what can only be described as a terrific, thunderous and spectacular sight. MDI would like to thank bikers, Joe Kleuters and his wife Carina from MDA Europe in Holland, who invited MDI to this rally and helped raise a total of **€3,100.00** for MDI.



*Staff and volunteers at the MDI stand at the HOG rally.*

## GAA Football Final Tickets Raffle

In September MDI held its first draw for two All-Ireland Football Final tickets. Shops, pubs and newsagents in Mayo and Kerry took part in the draw for the tickets. Many thanks to all staff and members who supported this event and helped make it a success. MDI also wish to sincerely thank Mr Brian McNulty, who gave his time very generously to help with the raffle, in which we raised a total of **€7,000.00** for MDI.



## **Contact Details**

### **Head Office:**

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71/72, North Brunswick Street  
Dublin 7

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Freephone: 1800 245300

Fax: 01 8724482

Email: [info@mdi.ie](mailto:info@mdi.ie)

Website: [www.mdi.ie](http://www.mdi.ie)

### **MDI Head Office Staff:**

Joe Mooney, Director  
Aileen O'Mahony, Administration Coordinator  
Kate Power, Respite Coordinator  
Margaret Goode, Family Support and Clinic Coordinator  
Karen Pickering, Information Officer  
Fiona O'Donoghue, Administrator  
Hazel Bridcut, Accounts  
Hubert McCormack, Administrator  
Antoinette Roche, Administrator  
Fundraiser (*to be appointed*)

### **MDI Regional Offices:**

Muscular Dystrophy Ireland  
Unit 24, Westside Centre  
Model Farm Road  
Cork  
Tel: 021 4348442

Muscular Dystrophy Ireland  
North Eastern Health Board  
Climber Hall  
Kells  
Co. Meath  
Tel: 046 9280026

Muscular Dystrophy Ireland  
Disability Offices  
Offaly Exhibition and Research Centre  
Bury Quay  
Tullamore  
Co. Offaly

Muscular Dystrophy Ireland  
Unit 4, Business Centre  
Market Yard  
Sligo  
Tel: 071 9140210

### **Family Support Workers:**

#### **East Coast and South Western HSE Area (South Dublin Coast, Wicklow, South West Dublin, Kildare):**

Eithne Diamond: ~~Eithne Diamond~~: 086 3830966

#### **Northern HSE Area (North Dublin):**

Catherine Logan: ~~Catherine Logan~~: 086 3834428

#### **North Eastern HSE Area (Cavan, Louth, Meath, Monaghan):**

Liz Lacey: ~~Liz Lacey~~: 086 6066105

#### **North Western HSE Area (Donegal, Leitrim, Sligo):**

Fintan Flannery: ~~Fintan Flannery~~: 086 3899279



**Western HSE Area (Galway, Mayo, Roscommon) and Midlands HSE Area (Longford, Offaly, Westmeath):**

| Lisa Fenwick: ~~Caroline Moran~~: 086 6066106

**Mid-Western HSE Area (Clare, Limerick, North Tipperary):**

| Steph Apsel: ~~Steph Apsel~~: 086 3879159

**South Eastern HSE Area (Carlow, Kilkenny, South Tipperary, Waterford, Wexford):**

| Marie Kealy: ~~Marie Kealy~~: 086 6066107

**Southern HSE Area (Cork, Kerry):**

| Trudy Renshaw: ~~Trudy Renshaw~~: 086 3899266

**Youth / Respite Workers:**

**Eastern Region (Dublin, Kildare, Wicklow):**

| Karen Leonard: ~~Karen Leonard~~: 086 6066109

**North Eastern Region (Cavan, Louth, Meath, Monaghan):**

| Emma Carrass: ~~Brenda Hopkins~~: 086 6066108

**Midlands Region (Laois, Longford, Offaly, Westmeath):**

| Stephanie Fagan: ~~Sinead Glennon~~: 086 3899285

**Western Region (Galway, Mayo, Roscommon):**

| Aisling Dermody: ~~Aisling Dermody~~: 086 3899286

**Southern Region (Cork, Kerry):**

| Ciara Kelly: ~~Mary-Rose Howell~~: 086 6066104

**Drivers:**

**Eastern Region:**

Robert Dowd: 086 3899262

**Southern Region:**

Jim O'Donovan: 086 8207872

## **Acknowledgements**

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Thank you to everyone who once again supported the National Awareness Day, especially Spar, Roches Stores, Interlink Couriers and Fast Track, who assisted with distributing the chocolates.

MDI relies on the support of members and tremendous thanks must go to all those who have tirelessly raised awareness and funds through the selling of chocolates, Christmas cards, participating in the mini marathon and various other events throughout the country.

**Your support is ensuring that MDI is growing from strength to strength.**