Muscular Dystrophy Ireland

ANNUAL REPORT 2007
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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 celebrated 35 years of providing support to people with muscular dystrophy and their families.

Mission Statement

Muscular Dystrophy Ireland aims to provide information 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 advocating for 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, all MDI members and friends,

This has been another very busy and exciting year for MDI. Over the past twelve months MDI has endeavoured to increase our Family Support, Youth Respite Services, Respite, Transport, Information services, etc, nationwide. Increasing these supports and services takes financial support, so I would like to take this opportunity to thank all the Health Service Executive areas who continue to provide financial support, and to all MDI members and friends for their tireless fundraising endeavours throughout the year. Funding is an ongoing battle for the organisation. These increases in supports and services are outlined in this report.

Another exciting area is in research, where at present there are Exon Skipping clinical trials taking place in the UK by the MDEX consortium, and by all accounts there is very favourable feedback so far.

I would like to thank Ms. Florence Dougall, National Chairperson, and the National Executive and Council members 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 2008 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
The year 2007 proved to be a continuation of the already commenced enhancement and expansion of essential services for members of Muscular Dystrophy Ireland. Three positions within the Organisation were further developed, which were; a full time Fundraising & PR Coordinator, a full time Family Support Worker in the Dublin South West and East Coast Area (which had previously been a part time position), and full time Driver/Fleet Coordinator in the Dublin Area.

Staff development is ongoing through training and refresher courses, all towards the aim of delivering the highest standard of service to members.

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**Highlights of 2007**

**February 2007**
MDI’s 6th Annual Awareness Day on St. Valentine’s Day continued to be a great success and thanks to all who helped out before, during and after this campaign.

**March 2007**
On Saturday, 10th March, 2007, MDI held an information day for members focusing on “The Management of Muscular Dystrophy”. The day was well attended and thanks to all concerned for making it a great success. A full report is available for anyone interested.
April 2007

Prior to the MDI AGM on 28th April 2007 in Laois, there were two presentations on research which MDI is financially supporting:

- Dr. Matthew Wood from the UK Exon Skipping consortium presented an update on their research to-date
- Professor Kay Ohlendieck presented on her research project entitled: “Identification of novel biomarkers in dystrophic heart and muscle fibres using comparative proteomics”.

Summaries of both these presentations are also available from the Head Office.

May - September 2007

MDI Respite Camps 2007

Four MDI camps were held between May and September 2007 at which 55 members attended. These camps were held in Armagh, Fermanagh and Roscommon and provided essential breaks for members and parents alike.

Women’s Mini Marathon

The Flora Women’s Mini Marathon took place in Dublin on the June Bank Holiday weekend and we had a great turnout with over 100 participants who raised over €17,000. Well done to all and thanks.

October 2007

“Integr8”, an interactive DVD for Youth Clubs in Ireland was officially launched by Minister Sean Haughey on the 17th October in the Blanchardstown Library. Copies are available from Head Office.

MDI Delegation Meets Dr. Jimmy Devins TD

On Thursday 18th October 2007, a delegation from MDI travelled to Dáil Éireann to meet with Dr. Jimmy Devins TD, Minister of State with responsibility for Disability and Mental Health. The purpose of this visit was to raise awareness of the work of MDI and to try to source funding for MDI services and research. MDI is pleased to be raising the profile of the organisation among government ministers, and trying to bring to the forefront, the issues affecting people with muscular dystrophy and their families.

FUNDRAISING

Also in October, MDI held a Greyhound Race Night at Newbridge Greyhound Stadium on Saturday the 20th. This event was a huge success and raised over €20,000 for MDI. Thanks again to all concerned and particularly Eamon Nolan from Newbridge for, once again, initiating this event and helping to make it a great success.

I would also like to thank everyone else involved with fundraising. The many other fundraising events in 2007 were very successful and I would like to urge continued enthusiasm by members and friends to enable these events to become even more successful.

RESEARCH

On the topic of research, MDI continues to support and fund research into muscular conditions. Overviews of this research are encouraging. Without the tireless fundraising activities of members MDI would not be in a position to fund this research.

MEMO & ARTICLES

MDI’s Memo & Articles were produced in 1977 and, as the organisation has grown considerably since then, this document was reviewed in the past year.
During 2007 MDI 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.

I would like to extend a word of thanks to the various Health Service Executive Departments for their financial support in 2007 and over the past number of years.

In addition, I would like to thank the Dept. Justice, Equality and Law Reform, for once off funding in the amount of €262,699 which enabled MDI to purchase new buses and equipment to help provide greater independence for many of our members.

Thanks also to Dr. Bryan Lynch and his team at the Central Remedial Clinic, and to Prof. Orla Hardiman and Dr. Richard Costello and their respective teams at Beaumont Hospital for their continued support of MDI.

In this final report as chairperson, I would like to thank the Director and staff of MDI for their help and support to me for the past three years, and for their extremely hard work towards the continued success of MDI. I would also like to extend a big thank you to my fellow colleagues on the National Executive and Council committees for their commitment and support to me and MDI. Also to the members who sit on the Research and Trust Fund committees for their tireless work.

It was an honour for me to hold the position of Chairperson and I now look forward to supporting my successor in their role.

Regards,

Florence Dougall
National Chairperson
Muscular Dystrophy Ireland
MDI Offices

MDI’s Head Office is based in Dublin, where management and administration teams are based, along with national services including information, research and fundraising. The Administrative team in Head Office strives to develop MDI as a professional organisation in order to deliver the highest standard of support to members.

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.

During 2007 two of our offices moved premises – Tullamore and Sligo. The new contact details can be found at the back of this report.

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.

Head Office Staff

Front L-R: Hubert McCormack (Administrator), Amy Bramley (Fundraising & PR Coordinator), Laura Leeson (Receptionist).

Back L-R: Karen Pickering (Information Officer), Fiona O’Donoghue and Antoinette Roche (Administrators).

Not pictured: Hazel Bridcut (Accounts).
Muscular Dystrophy Ireland has

- 477 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.
- 26 Core Staff, 9 Respite Care Workers and a bank of camp workers and PA’s nationwide.

**Breakdown of Members by County**

<table>
<thead>
<tr>
<th>County</th>
<th>Number of Members with MD</th>
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</thead>
<tbody>
<tr>
<td>Carlow</td>
<td>3</td>
</tr>
<tr>
<td>Cavan</td>
<td>8</td>
</tr>
<tr>
<td>Clare</td>
<td>21</td>
</tr>
<tr>
<td>Cork</td>
<td>15</td>
</tr>
<tr>
<td>Donegal</td>
<td>60</td>
</tr>
<tr>
<td>Dublin</td>
<td>139</td>
</tr>
<tr>
<td>Galway</td>
<td>19</td>
</tr>
<tr>
<td>Kerry</td>
<td>10</td>
</tr>
<tr>
<td>Kildare</td>
<td>19</td>
</tr>
<tr>
<td>Kilkenny</td>
<td>10</td>
</tr>
<tr>
<td>Laois</td>
<td>9</td>
</tr>
<tr>
<td>Leitrim</td>
<td>4</td>
</tr>
<tr>
<td>Limerick</td>
<td>18</td>
</tr>
<tr>
<td>Longford</td>
<td>4</td>
</tr>
<tr>
<td>Louth</td>
<td>17</td>
</tr>
<tr>
<td>Mayo</td>
<td>11</td>
</tr>
<tr>
<td>Meath</td>
<td>23</td>
</tr>
<tr>
<td>Monaghan</td>
<td>10</td>
</tr>
<tr>
<td>Offaly</td>
<td>9</td>
</tr>
<tr>
<td>Roscommon</td>
<td>8</td>
</tr>
<tr>
<td>Sligo</td>
<td>2</td>
</tr>
<tr>
<td>Tipperary</td>
<td>9</td>
</tr>
<tr>
<td>Waterford</td>
<td>5</td>
</tr>
<tr>
<td>Westmeath</td>
<td>7</td>
</tr>
<tr>
<td>Wexford</td>
<td>20</td>
</tr>
<tr>
<td>Wicklow</td>
<td>18</td>
</tr>
</tbody>
</table>
MDI’s Information Officer, Karen Pickering, 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 2007, a total of 243 requests were received by the Information Officer. This is an increase on 2006’s total of 222 and 2005’s of 213. The chart below demonstrates how this figure is broken down by region.

The chart below shows the types of information most frequently requested. Most people ask for information about muscular dystrophy, followed by information about the support that MDI provides to individuals and families affected by the condition.

As well as the people asking directly for information about research and entitlements, anyone who is on the mailing list would also receive research updates and entitlements news in the MDI News Update.
The Management of Muscular Dystrophy

On Saturday 10th March 2007, MDI held an information day for members focusing on “The Management of Muscular Dystrophy”. There were some very informative and interesting presentations on subjects including physiotherapy (Pamela Foley, Central Remedial Clinic), occupational therapy (Rachel Glennane, CRC), respiratory management (Prof. Richard Costello, Beaumont Hospital) and cardiac monitoring and treatment (Dr. Afif El-Khuffash, Our Lady’s Hospital, Crumlin). Thank you to all the speakers who gave their time to attend on the day, and also to the HSE for providing funding towards the running of the day.

Newsletter and Website

The MDI News Update is sent out to members and other interested parties every two months. In 2007, the newsletter began to be professionally printed in full colour, which improves the reading experience. 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. Readers are asked to contribute to the newsletter, in the form of stories, articles or photos, and these can be sent to the Editor in Head Office.

870 people are on the mailing list to receive the MDI News Update, and each issue is downloaded via the website by a further 350-450 people every issue.

The MDI website, www.mdi.ie also received a new look in 2007. The new updated website will allow more access to information and represents a more professional face to MDI.
MDI employs eight Family Support Workers (FSWs) nationwide. MDI’s commitment to provide a FSW for every member is part of our mission to assist members to lead full lives and to contribute to their community. Our FSWs come from a range of healthcare related backgrounds and strive to provide a friendly professional service both individually and as a team.

The role of the FSW is to provide a quality family support service in order to best meet the needs of our members, which may change over time. Our support may be in the form of phone calls, home visits or facilitating social outings, and includes emotional support, providing information, support with decision making, liaising with other agencies and advocating for entitlements. Additionally, FSWs liaise on a regular basis with other MDI staff such as Youth Workers, Clinic Coordinator, Drivers, Information Officer, Respite Coordinator and other office staff so that our members and their families receive the best support available. FSWs endeavour to support members’ present needs and to also prepare for future challenges. Please let us know how we can support you and your family.

In 2007, MDI Family Support Workers provided 474 home visits to families nationwide, in addition to the support and information provided by phone and electronic means.

Six social outings for adults with muscular dystrophy took place in 2007.
The respite service is an essential support for people with muscular dystrophy and their families. Services are coordinated by the Respite Coordinator, 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 Definition of Respite**

Respite care is short-term care that helps a family take a break from the daily routine and stress. Respite care can occur in the person’s/family home or in a variety of out-of-home settings, and can occur for any length of time depending on the needs of the family and available resources. MDI recognises that the person/child with muscular dystrophy and family members both need to avail of respite care services in order to maintain physical and emotional wellbeing.

**MDI Respite Services Expenditure 2003-2007**

<table>
<thead>
<tr>
<th>Year</th>
<th>€</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>€256,696</td>
</tr>
<tr>
<td>2004</td>
<td>€392,632</td>
</tr>
<tr>
<td>2005</td>
<td>€479,121</td>
</tr>
<tr>
<td>2006</td>
<td>€567,407</td>
</tr>
<tr>
<td>2007</td>
<td>€608,584</td>
</tr>
</tbody>
</table>

As you can see MDI is prioritising and funding more respite services each year. Respite services are categorized as summer camps, personal assistant hours, respite breaks provided in the home, holidays and financial contributions. In 2007 the organisation spent €608,584 on respite services to members, an increase of €41,177 from the previous year.
**The Youth Service**

Youth / Respite workers provide visits to members in their homes, youth clubs, and social outings. Home visit activities can include helping with homework, arts and crafts, baking, board games, watching DVDs, play station, going for walks etc. Youth clubs and social outings have included trips to the cinema, bowling, going for lunch, shopping, playing power soccer, picnics, pet farms, the zoo, museums, play centres, play station tournaments, and visits to places of interest. There were also workshops ran during the summer of 2007, with members in Dublin taking part in a music workshop, and members in the midlands area taking part in a photography workshop. Both of these were very successful and enjoyed by all who took part.

MDI’s Youth / Respite Workers provided 395 home visits, 89 social outings and 122 youth clubs throughout the country in 2007.

**Power Soccer**

Power soccer is soccer designed for power chair users. Teams are mixed, and all ages are welcome to take part. At the moment it is our younger members who are filling up the teams, but power soccer is open to everyone. The only requirement is that you are a power chair user.

This year we had power soccer days on a regular basis throughout the country, where players from different regions got the chance to meet up, train their skills, and get some match practice in. Then in July, the National Power Soccer Day was held in Limerick, with teams from around the country taking part. A great day was had by everyone, especially Aisling McElligott, Ciarán Donoghue, Maureen Brennan and Aoife McNicholl, who went home with the All Ireland Cup.

**Respite Breaks**

This year MDI’s respite camps proved to be as popular as ever, with members from all over the country taking part. These camps, while providing members with a break away and the opportunity to meet up with old and new friends, also give parents and carers a break.

Four respite breaks took place in 2007, with a total of 55 members of MDI participating.

<table>
<thead>
<tr>
<th>Camp</th>
<th>Venue</th>
<th>Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>April Camp 07</td>
<td>Share Village, Co. Fermanagh</td>
<td>15</td>
</tr>
<tr>
<td>May Camp 07</td>
<td>Cuisle, Co. Roscommon</td>
<td>13</td>
</tr>
<tr>
<td>July Camp 07</td>
<td>Ti-Chulainn, Co. Armagh</td>
<td>16</td>
</tr>
<tr>
<td>August Camp 07</td>
<td>Cuisle, IWA, Co. Roscommon</td>
<td>11</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>55</strong></td>
<td></td>
</tr>
</tbody>
</table>

Members participated in activities such as table quizzes, comedy nights, power soccer, Easter parades, canoeing, archery, discos etc.
Respite Care Workers / Personal Assistants

MDI provides personal assistant (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 2007 MDI supported 23 families nationwide by employing respite care workers to support the member and family. Family Support Workers continue to work closely with the HSE and other service providers in identifying and prioritising funding for personal assistant hours for members.

In addition MDI also supported 18 members / families throughout the country by funding care workers to support short term respite breaks in the home e.g. holidays, nights out, weekend breaks and hospital appointments.

MDI supported an additional 7 members during emergency periods until the HSE allocated the necessary funding.

Under financial contributions the organisation supported 23 families with the cost of respite holiday and 14 families with the cost of medical expenses not funded by the HSE e.g. physiotherapy, counselling, art therapy etc. The financial contribution section is a small limited budget and priority will is given to assisting members with medical costs and equipment.

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 currently being run by Dr. Ronan Walsh, 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.

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

Minister Sean Haughey launched ‘Integr8’ an interactive DVD for youth clubs in Ireland

The Minister of State Sean Haughey T.D. launched in October 2007 ‘Integr8’; a new interactive youth work DVD, which aims to increase awareness of the needs, desires and wants of young people with physical disabilities. The project was funded by the Irish Youth Foundation and directed by Muscular Dystrophy Ireland, Irish Wheelchair Association and Foróige and will be distributed amongst 400 youth organisations around Ireland.

According to Joe Mooney, Director of Muscular Dystrophy Ireland, the idea behind the DVD was that people with disabilities could set the agenda for young people with a disability. We hope that it will prove to be a very useful tool. “Muscular Dystrophy Ireland strives to promote through physical empowerment, independent living for people with the condition so that they may fully participate in society and live a life of their own choosing. ‘Integr8’ is very much in keeping with this ethos and MDI is delighted that it will be used in youth organisations all over Ireland,” he said.
In 2007 MDI developed new roles including a full time Fundraising & PR Coordinator, a full time Family Support Worker in the Dublin South West and East Coast Area (which had previously been a part time position), and full time Driver/Fleet Coordinator in the Dublin Area.

**TRAINING**

MDI recognises that its staff are its most important resource and is committed to the planned continuous development of staff for the mutual benefit of the individual and the organisation. Staff joining the organisation undergo an induction programme to introduce them to their role, organisational policies and procedures and the organisation as a whole. Through training, staff development and support, our aim is to continue to deliver the highest standard of care and service to our members.

Training that took place in 2007 included:

**DATA PROTECTION & FREEDOM OF INFORMATION TRAINING**
In November 2007 all MDI completed a days training in ‘Freedom of Information and Data Protection-Implications for Recording’ which was provided by Phil Mortell, Principal Social Worker, Organisation Development Unit, HSE West.

**MiDAS (MINI-BUS DRIVER AWARENESS SCHEME) TRAINING**
MiDas, the Minibus Driver Awareness Scheme, is a programme developed to enhance the driving and passenger awareness skills of the many thousands of individuals who drive minibuses in the course of their work or on a voluntary basis. The scheme has resulted from a detailed study of minibus driving and a lengthy period of consultation with voluntary and statutory groups which operate minibuses. MiDAS is designed to make appropriate assessment, training and accreditation available to minibus drivers from voluntary organisations, schools, colleges, and local authorities at a local level.

During 2007, MDI Drivers, Youth Respite Workers and a group of MDI members completed the two day MiDAS training course in the Midlands and Southern region.

**NEUROLOGY TRAINING NETWORK**
MDI also participated in the Neurology Training Network in 2007. 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.

In 2007, Family Support Workers and Head Office staff completed training in Managing Volunteers, Helpline Training, Supporting your Support Groups and Neurological Training.

**CITIZENS INFORMATION BOARD TRAINING**
The Citizens Information Board is the statutory body which supports the provision of information, advice and advocacy on the broad range of social and civil services to the public. During 2007, Information Officer and Family Support Workers completed training in ‘Disability Payments, Entitlements and Work Options’.

**IRISH WHEELCHAIR ASSOCIATION (IWA) TRAINING**
All respite care, personal assistants and youth respite workers are qualified in moving and handling and core competency which is a 2 day course covering Disability Awareness, Care Practice, Safety legislation and Work Safety and Child protection.

This training continued throughout 2007 with refresher courses happening for some staff in early 2008.

**SKILL VEC TRAINING PROJECT**
The ‘SKILL Project’ is funded by the Health Service Executive and administered by the Disability Federation of Ireland. The courses run at the Vocational Educational Colleges around the country. SKILL Project was developed from research carried out in 2004-2005 which highlighted the skills, knowledge, traits and motivation needed for care staff to increase their efficiency and skills. These programmes are designed to meet FETAC accreditation standards and take place at a local level.

Three Respite Care Workers from MDI completed the SKILL Project during 2007 in regional VEC colleges.

Policies and Committees

MDI is continuing to strive to develop the professionalism and services of the organisations. We continued to develop policies and procedures to ensure we can carry out our aims and objectives to the highest possible standard.

In Health and Safety, new transport manuals and staff protection guidelines were published. Committees continued in different areas related to improving the respite, family support, youth, transport and information service. We are hoping to set up a fundraising committee in 2008.

The organisation has attended many meetings and conferences regarding the upcoming Charities Bill in order to ensure compliance with any legislative changes within the charity sector.

Memo & Articles and Branch Guidelines

MDI’s Memo & Articles were produced in 1977, and as the organisation has grown considerably since then, this document had to be reviewed. The process to date has been as follows:

- Began in 2006
- 3 consultation meetings nationally in 2006
- Feedback was given to MDI National Council in 2006
- Recommendations were implemented into the documents
- Draft documents were circulated to MDI National Council in 2007
- Final drafts to be presented at MDI Annual General Meeting in 2008

Branch Guidelines were developed in 2002 and the revised edition of these will be presented at the MDI AGM in 2008.

MDI Delegation Meets Dr. Jimmy Devins TD

On Thursday 18th October 2007, a delegation from MDI travelled to Dáil Éireann to meet with Dr. Jimmy Devins TD, Minister of State with responsibility for Disability and Mental Health. The purpose of this visit was to raise awareness of the work of MDI and the need for future funding of the organisation, the difficulties facing members trying to access community services such as physiotherapy, occupational therapy and personal assistance, and to raise awareness of the MDEX Consortium beginning clinical trials and trying to source funding for this research.

MDI is pleased to be raising the profile of the organisation among government ministers, and trying to bring to the forefront, the issues affecting people with muscular dystrophy and their families.

MDI Delegation who met with Dr Devins TD:
(Front): Joe Mooney, Director; Hubert McCormack, Administrator
(Back): Jimmy Mooney, member of MDI; Kate Power, Respite Coordinator; Karen Pickering, Information Officer
MDI currently funds two research projects, Prof. Kay Ohlendieck, Head of Biology in NUI Maynooth, for "Identification of Novel Biomarkers in Dystrophic Heart and Muscle Fibres Using Comparative Proteomics", and 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".

MDI Information Officer, Karen Pickering, presents a cheque to the MDEX Consortium for their research.

On 2nd April 2007, Ms. Mary Harney, Minister for Health, officially announced the recipients of the Medical Research Charities Group / Health Research Board Joint Funding Scheme 2006, in the Royal Irish Academy, Dublin. MDI received part funding for the above two research projects, and Mr. Joe Mooney, Director, Mrs. Karen Pickering, Information Officer, and Prof. Kay Ohlendieck, grant recipient, attended the official announcement. MDI would like to thank the MRCG and the HRB for the opportunity to participate in this scheme.

Prof. Ohlendieck and Dr. Matthew Wood from the MDEX Consortium, attended the MDI AGM on Saturday 28th April 2007 in Portlaoise, to give an overview of their research. This was very informative and MDI would like to thank both speakers for giving their time to address the meeting.

Without the tireless fundraising of MDI members, the organisation would not be in a position to fund any research projects. Thank you to everyone involved in securing this funding.

LEFT: MDI Information Officer, Karen Pickering, presents a cheque to the MDEX Consortium for their research

BELOW: Pictured at the MDI AGM in 2007 (Front): Joe Mooney, Director; Florence Dougall, Chairperson (Back): Dr. Matthew Wood, Prof. Kay Ohlendieck
MDI has three national fundraising events throughout the year, the National Awareness Day, the Flora Women’s Mini Marathon and Christmas card sales. Members of MDI also take part in local fundraising events, such as greyhound nights and table quizzes, to raise funds and awareness.

In 2007, MDI welcomed Amy Bramley to the team as full time Fundraising and PR Coordinator. A new fundraising tool was also launched, as MDI signed up to a new and fundamental web based fundraising and donation service, mycharity.ie. Via a link on the MDI website, visitors to www.mycharity.ie can make a donation to MDI, set up their own fundraising page where you can select MDI to fundraise for, and sponsor a friend who is participating in a fundraising event for MDI. For more information, contact Amy in Head Office.

National Awareness Day 2007

Muscular Dystrophy Ireland’s “Have a Heart” National Awareness Campaign which was held on the 14th February 2007, was a tremendous success due to the fantastic support MDI received from members, friends and staff who assisted in the promotion and sale of the Lily O’Brien’s Chocolates and most importantly increasing the awareness of the condition nationwide.

The Campaign was officially launched by TV3 weatherman Martin King, Katie Taylor, the World Lightweight boxing champion and MDI member Simon Jameson supported and represented MDI in what was the 6th Awareness Day and most successful to date. MDI had coverage in the press, radio and TV, where Marcella & Ronan Gavigan along with Dr Bryan Lynch, Consultant Paediatric Neurologist, appeared on the Afternoon Show on the 12th February 2007.

MDI also had great support once again from the cast of Fair City and both members Jason Connolly and Kevin Gannon from Dublin were delighted to attend the photo shoot in RTE’s Fair City Studio before the campaign commenced.

MDI members and volunteers sold Lily O’Brien’s chocolates in Debenhams stores nationwide on the 12th, 13th & 14th February.

A special thanks to the sponsors of the 2007 Awareness Campaign: Spar, Debenhams, Interlink, FasTrack and Budget Travel
Flora Dublin Women’s Mini Marathon
A great day was had by all the members, friends and staff of MDI who took part in the Mini Marathon on the 4th June 2007. The tremendous sum of €17,948 was raised by all the fantastic participants and supporters.

The Mini Marathon is a great way to help raise money, increase the awareness of the condition and the important role MDI plays in the lives of the individuals and families who are affected by muscular dystrophy.

MDI Christmas Cards 2007
As part of our annual fundraising efforts MDI sold Christmas Cards, a pack of cards contained a verity of twelve cards and cost €7.00. They were distributed nationwide to members, friends, shops and other outlets and thank you to everyone who sold and bought the cards.

The Christmas cards are available every year from Head Office and we look forward to a new range of cards for Christmas 2008.

Greyhound Race Night, Newbridge
Muscular Dystrophy Ireland held the second Benefit Greyhound Race Night at Newbridge Greyhound Stadium on Saturday the 20th October 2007. This event was a tremendous success and raised over €20,000 for MDI. It was a great night for all those who attended, a winning success for MDI and all parties involved. MDI would like offer sincere appreciation and thanks to our main sponsor on the night, Pat Fitzsimons of Parfit Ltd and MDI would like to thank all the companies, businesses and private individuals who sponsored races, placed adverts in the racing booklet and kindly donated money and prizes. A special word of thanks to Eamon, Mary & Andrew Nolan, Ber, Anne & David Tyrell Dillon who contributed so much time and effort in organising this Race Night.
FUNDRAISING FOR RESEARCH

Several members are tirelessly fundraising for research into muscular dystrophy. One of these is Imelda Quinn and friends of the Donegal Branch of MDI, who raised €7,225.00 for research into muscular dystrophy. This money was raised by a variety of fundraising activities held throughout the summer of 2007, which were organised by Imelda and friends of the “Patrick Quinn Committee”. Thank you to all who donated kindly.

Joe Mooney (front left) with friends of the “Patrick Quinn Committee”
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Freephone: 1800 245300
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Email: info@mdi.ie
Website: www.mdi.ie

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Margaret Goode
Karen Pickering
Fiona O’Donoghue
Hazel Bridcut
Amy Bramley
Hubert McCormack
Antoinette Roche
Laura Leeson
Director
Administration Coordinator
Respite Coordinator
Family Support & Clinic Coordinator
Information Officer
Administrator
Accounts
Fundraising & PR Coordinator
Administrator
Administrator
Receptionist

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Muscular Dystrophy Ireland
North Eastern Health Board
Climber Hall
Kells, Co. Meath
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Muscular Dystrophy Ireland
Old Medi Centre
Kempton Parade
Sligo
Tel: 071 9140210

Muscular Dystrophy Ireland
Roxboro House
Raleigh Row
Galway
Tel: 091 583890
### Family Support Workers

<table>
<thead>
<tr>
<th>Area</th>
<th>Contact Person</th>
<th>Phone</th>
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</thead>
<tbody>
<tr>
<td>East Coast &amp; South Western HSE Area</td>
<td>Julie-Ann Coleman</td>
<td>086 3830966</td>
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<tr>
<td>North Eastern HSE Area</td>
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<td>North Dublin</td>
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<tr>
<td>Cavan, Louth, Meath, Monaghan</td>
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<td></td>
<td>while Liz Lacey is on leave</td>
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<tr>
<td>North Western HSE Area</td>
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<td>Donegal, Leitrim, Sligo</td>
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<tr>
<td>Longford, Offaly, Westmeath</td>
<td>Lisa Fenwick</td>
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<td>Clare, Limerick, North Tipperary</td>
<td>Steph Apsel</td>
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<td>Carlow, Laois, Kilkenny, South Tipperary, Waterford, Wexford</td>
<td>Marie Kealy</td>
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<tr>
<td>Cork, Kerry</td>
<td>Trudy Renshaw</td>
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### Youth / Respite Workers

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<thead>
<tr>
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<tr>
<td>Dublin, Kildare, Wicklow</td>
<td>Karen Mooney</td>
<td>086 6066109</td>
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<tr>
<td>Cavan, Louth, Meath, Monaghan</td>
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<tr>
<td>Laois, Longford, Offaly, Westmeath</td>
<td>Sinead Glennon</td>
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<tr>
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<tr>
<td>Galway, Mayo, Roscommon</td>
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<td>Southern Region</td>
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<tr>
<td>Cork, Kerry</td>
<td>Mary-Rose Howell</td>
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### Drivers

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<tr>
<td>Southern Region</td>
<td>Jim O’Donovan</td>
<td>086 8207872</td>
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*Muscular Dystrophy Ireland Annual Report 2007*
MDI would once more like to thank the Health Service Executive for their continued support. Without this funding, MDI would not be in a position to maintain the high standard of support for members throughout the country. Thank you to everyone who once again supported the National Awareness Day 2007, especially Spar, Debenhams, Interlink Couriers and Fast Track, who assisted with distributing the chocolates.

Thank you to all MDI staff for their hard work throughout 2007, including all our respite care workers, volunteers and PA’s who put in tireless work during the year to make respite breaks and camps so enjoyable.

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