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 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. We also aim to support and fund research into neuromuscular conditions.
Dear All,

Once again it has been an eventful year as the organisation continues to grow. During the last year MDI has continued to create awareness of the needs of our members. This has been achieved by our fourth National Awareness day in February, which was another great success. This awareness and fundraising event would not have been so successful without the hard work of members, staff and volunteers nationwide to whom we owe our gratitude. Also our Christmas card sales proved a huge success this year.

During the year we welcomed many new members of staff, including a new respite coordinator, responsible for organising respite, supporting Youth/Respite Workers nationwide and organising summer camps for our members. Further, we also welcomed a new FSW/clinic coordinator, who facilitates members’ usage of the Central Remedial Clinic and the Beaumont Hospital Clinic and supports our FSW’s nationwide. Two more FSW’s have joined us, one in the Midwestern area and the second in the North Eastern area. MDI also employed a minibus driver in the Southern Region. Finally, we are also pleased to welcome a new Youth/Respite worker in the Western area.

Many organisations, including MDI, are facing a lot of operational challenges as a result of required changes in the work practice of the community and voluntary sector in response to the implementation of benchmarking increases and pay agreements. Therefore, there is currently a strong focus within MDI on the administration policies and procedures. To that end, MDI completed its Code of Practice and Policy for the Protection of Young People in 2004. This document gives guidelines and identifies the best practice for Youth/Respite Workers, PAs and Volunteers to use when working with young people. Further, a Staff Handbook was also developed in late 2004 in collaboration with all staff to outline employment legislation and best practice, policies, and procedures for staff and management to follow.

Looking towards the year ahead, MDI will be concentrating on further developing its services to members and administrative procedures. One implementation of this goal is the development of a new database that will record work executed by MDI. This information will give an accurate and detailed picture of MDI’s operations, which is vital to continued success in securing funding from the Health Service Executive. MDI will also continue to work on ensuring that all Health and Safety aspects of the organisation comply with legislated requirements.
MDI welcomed the publication of the Disability Bill at the beginning of June. Although MDI would not have accepted all of its contents we will work to ensure that its recommendations are carried out. This bill will be reviewed in three years time and MDI will ensure that we will be involved in this process.

Professor Ohlendieck has completed his three year research project called "Identification of Novel Therapeutic Targets in Dystrophic Muscle Fibres". We look forward to seeing his team’s results.

On behalf of MDI and its members I would like to extend a word of thanks to all the Health Boards 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 her team 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 also like to sincerely thank the Director and staff for their continued commitment to MDI.

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

Regards,

Florence
National Chairperson
Hi all members and friends of MDI,

This has been another very busy and exciting year for MDI. Over the past twelve months MDI has strived to increase our services to our members nationwide. To increase these services takes financial support, so I would like to take this opportunity to thank all the health boards for this support and all MDI members and friends for their fund raising support throughout the year.

The biggest service that is required by our members is the respite service. The demand for this service has grown dramatically over the past twelve months. MDI strive to meet the needs of our members. Another key area that has been highlighted by our members is in the areas of employment and training. MDI has addressed these issues by running information evenings and MDI has also applied for funding to employ an advocate to support members in this area.

MDI were delighted with the publication of the Disability Bill and look forward to the full implication that it recommends.

Over the past number of months there have been major changes in the Health Board Structure with the dissolution of the Health Boards into four regions, which will have implications for MDI. MDI has been putting plans in place over the past year to ensure that we are in a position at the forefront to tackle these changes.

I would like to thank the National Executive Committee, the National Council and all the members of MDI for their support and encouragement over the past year. 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 2006 brings and will strive to enhance the services that our members require. If anyone would like to contact me please feel free to do so.

Regards,

Joe T Mooney
Director
Muscular Dystrophy Ireland
Family Support Service

MDI has Family Support Workers based in the different regions of the country. Their role is to provide support to people with muscular dystrophy and their families, which could be in the form of home visits, telephone contact or group meetings, depending on what each individual requires. They also liaise with other teachers, occupational therapists, public health nurses etc. when required and act as advocates when trying to access services and resources for members.

Caroline Moran, MDI’s Family Support Worker in the west and midlands describes how the service has developed

The Family Support Service has developed considerably since I started in 1997. The number of support workers has greatly increased, we can now deliver a more localised service with FSW’s spread out across the country. This in turn has led to the development of new offices, which provide MDI staff with a work base and also provides a facility for members if required. I would hope that families have benefited from these changes and that they feel they have easy access to the service when it is required. I greatly welcome the development of the Youth/Respite Worker Service; it compliments the Family Support Service and it is very beneficial for the young members and their families. It is great that MDI continues to provide short term respite as it can meet families’ needs on a time to time basis or it acts as a stop gap until funding has been allocated by the Health Service.
Youth and Respite Service

MDI aims to provide respite to members, depending on individual requirements and availability of funding. The types of respite available include respite breaks and summer camps, emergency respite and night assistance. It is an essential service to enable people with muscular dystrophy, their families and carers to avail of a break and maintain a reasonable quality of life. To enquire about the respite service, contact Kate Power, MDI's Respite Coordinator, who is based in the Dublin office.

Youth / Respite Workers are based around the country and organise activities and youth clubs for children and teenagers with muscular dystrophy. They also visit young members in their homes for an afternoon to enable other family members to avail of a short break. The YRW's organised a range of trips throughout the year, including Mondello Park to see motorbike racing, Dublin Zoo, FOTA Wildlife Park in Cork and a trip to London to see Chelsea play Everton.

In 2004, various respite breaks took place. There was an adult members' trip to Clarenbridge, Galway and one to Westport. There were two summer camps, one for children and one for older teenagers, in the Share Village, Co. Fermanagh. Participants were able to try a range of activities, including pottery, rock climbing and archery.

Karen Leonard, Youth / Respite Worker in the eastern region, describes the young adults' break in Killarney

At the end of September a group of young adult members travelled to Killarney for a weekend away. Members from all over the country arrived at the Holiday Inn Hotel on the Thursday where we stayed for the weekend. For the first night we all settled for a few quiet drinks in the hotel but this was not to be the theme for the weekend! The next day, following a days shopping in Killarney we all headed off to the pub where there was a ballad band playing. For those still looking for a bit more lively music there was a nightclub nearby, where a bit more drinking and dancing was done. Some sore heads made it down to breakfast the next day. Then it was a trip into Tralee for some while others relaxed and recovered in the hotel. For the final night everyone went to The Gleneagle Hotel for dinner and a concert. By all accounts everyone had a great time even though we were all looking forward to getting back home to our own beds by the end of the weekend!

Mary Lambe, MDI member Fintan O'Reilly and Karen Leonard on a trip to the zoo
Above
MDI’s Power Soccer players being interviewed by TV Three

Left
The adult members respite break - visiting the Cliffs of Moher
Information Service

Karen Pickering is MDI’s Information Officer, based in the Dublin office

I receive information requests from a range of people wanting to know more about the different types of muscular dystrophy, about research developments, and about things that impact on their lives such as needing to find out about entitlements, accessible holidays, housing and transport to name a few. In 2004, there were 235 information requests, mainly divided between members and staff of MDI, medical professionals, teachers, special needs assistants and students doing projects about muscular dystrophy. These people received information packs tailored towards the type of information they were looking for, and were referred on to other services when required, such as the Family Support Worker service.

In June 2004 the All-Ireland Symposium on Neuromuscular Conditions was held in Dublin for medical professionals, mainly occupational therapists and physiotherapists. This was organised by MDI in conjunction with the UK Muscular Dystrophy Campaign and was intended to increase awareness of muscular dystrophy and serve as a forum where health care professionals could share information and best practice. The day was a great success and similar future events are anticipated.

The MDI newsletter now has a dedicated research section, which is intended to provide updates on the important research developments from around the world.

As knowledge about the different types of muscular dystrophy increases, the information that is available from MDI must be updated, and this is a continuing process. In the coming year the information packs will be expanded to ensure that people using the service have access to comprehensive and accurate information.
Transport

Noel Kavanagh is MDI’s driver in the Dublin region. He is available to provide transport for members requiring it, for example, to attend clinics, hospital visits and MDI events in the Dublin region. The transport service is expanding and in 2004, Jim O’Donovan commenced employment as a driver in the Cork region. Members can organise transport when required by contacting the Dublin or Cork offices.

MDI also has adapted vehicles available for members to hire and these are organised and maintained by Noel Kavanagh (contact the Dublin office for more information). The fleet is being increased in 2005 and this will increase the availability of transport to members.

A member of MDI from Galway writes about the benefit this has been to him

I would like to thank MDI for the use of the van. It has made a big difference to my life. I am able to travel with much more ease and without days of forward planning. It has given me a level of independence which I never had before. Weekend trips to Connemara, social outings etc. were the stuff of fantasy before borrowing the MDI van came into my life.

As a person who can’t travel by car any longer, the van has given me back my independence.

I can only say this from the bottom of my heart:
Go raibh maith agat MDI.

Padreaig,
MDI member from Galway
Fundraising

Once again, 2004 saw MDI members, branches and staff involved in a range of fundraising events for MDI.

**National Awareness Day, St. Valentine’s Day 2004**
MDI’s main national fundraising campaign has gone from strength to strength, and this year records were broken with proceeds from the sale of the boxes of two heart shaped chocolates reaching over €40,000. The new red packaging was very popular and highlighted the link between MDI’s fundraiser and St. Valentine’s Day. Not only were members out selling the chocolates in shopping centres and venues throughout the country, some also organised coffee mornings, and in 2004 some very popular mornings were held in Kildare and in the Blarney Park Hotel, Cork. Thank you to all members who put in such a tremendous effort to make sure the day was such a success.

**Dublin Women’s Mini Marathon**
MDI’s female members (and some men dressed up as women!) came together to run or walk the 10K course and raise funds and awareness for MDI. Thank you to everyone who was involved and raised over €6000. Participants met in the Café en Seine bar after the race to avail of some well earned sustenance and have a chance to socialise.

**Christmas Cards**
In 2004 a new range of Christmas cards was produced and once again, thank you to everyone who sold them for MDI.

---

*Steven Valentine*
Fundraising Officer

*National Awareness Day, Letterkenny*
Local Fundraising
As well as the national events, Branches and MDI members have been involved in a range of local fundraisers, including table quizzes and sponsored walks. Thank you once again to everyone.

MDI has sponsorship cards and t-shirts and can provide assistance to members who wish to set up or participate in a fundraising event. Contact Steven Valentine, MDI’s Fundraising Officer in the Dublin office for more information.
Administration

MDI has a National Council which meets four times per year, and its role is to determine MDI policy. The Chairperson of each local branch is automatically a member of the National Council. The Council is also made up of local branch members who are nominated by their branch and ratified at the AGM.

The National Executive Committee of MDI also sits on the National Council. The Executive Committee is comprised of a Chairperson, Vice Chairperson, Treasurer, Secretary and there is allocation for a further two members. This committee meets once a month to determine the management of MDI.

The Director, Mr. Joe Mooney, looks after the day-to-day management of MDI, in conjunction with the Executive Committee. Organisational decisions must be passed by the Executive Committee, and policy amendments or additions must be ratified by the National Council. In this way, the members of MDI own the organisation and participate in the decision making process.

The administration of MDI is co-ordinated through the Dublin office. Here, the management of resources (human, capital and financial) takes place, national events are planned and co-ordinated, fundraising activities are arranged and general administration takes place. The Director of MDI is supported by Aileen O’Mahony, Administration Coordinator, who joined the organisation in 2004, Antoinette Roche and Hubert McCormack. Hazel Bridcut deals with the accounts.
Research

In 2004, Professor Kay Ohlendieck’s team at NUI Maynooth, completed the second year of the MDI-funded research project "Identification of Novel Therapeutic Targets in Dystrophic Muscle Fibres". The team have identified that abnormal calcium handling plays a key role in muscular dystrophy and their work is adding to the general understanding of the pathophysiology of the condition. Scientific results acknowledging MDI’s funding have appeared in 3 peer-reviewed international journals in 2004.

Clinics

The children’s muscle clinic in the Central Remedial Clinic continues to run well, as does the adult clinic in Beaumont Hospital, which has been in operation since September 2002. MDI’s FSW / Clinic Coordinator, Margaret Goode, attends these clinics to provide support to individuals attending and their families.
The Growth of MDI

A bit about me for a change!

1989 was the year Ireland qualified for its first World Cup, Century Radio was launched, the Berlin Wall came down and I started working for MDI. This just gives you an indication of how long I’ve been with MDI. In this period, I’ve seen three World Cups, lasted longer than Century Radio, and the Berlin Wall may have come down, but the walls of MDI have expanded considerably, from a poky little office in Monkstown, to our spacious offices today at 71/72 North Brunswick Street.

Given the above, you will be forgiven for thinking that I am the longest serving member of staff with MDI, but actually I’m not. Many of you will be familiar with the "telephone voice of MDI", the "behind the scenes" person who has served MDI loyally since 1988, Ms. Antoinette Roche. Antoinette actually started with MDI in May 1988 and was based in MDI’s first office (which we acquired in 1986) in Monkstown, and basically consisted of a desk and a telephone line!

Since then, MDI have moved offices on three occasions, as staff and services increased. In 1988, we moved to prefabricated offices in Christchurch Place (on the site of the now Jury’s Inn Hotel), and from there to Carmichael House in 1990 and Coleraine House in 1999, before settling into our current offices. So you could say that Antoinette and I are well settled, despite moving offices on four occasions!

Other changes over the years, to briefly mention a few, have included an increase in staff, services and transport. With just two part-time staff when I started, MDI now have 25 employees (excluding care workers), offices in Dublin, Cork, Galway, Sligo, Tullamore and Kells, and a fleet of wheelchair accessible vehicles available to members. These changes give an indication of how MDI has grown.

From being involved with organising coffee mornings to conferences, marathons to meetings, selling Christmas cards to selling chocolates, writing newsletters and welcoming new faces, I’ve been here for it all, and I see the above changes as being very positive and extremely beneficial to members. Long may it continue!

Hubert McCormack
Administrator, MDI
Acknowledgements

MDI would once again 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 services for all members.

Thanks also go to everyone who supported the National Awareness Day, especially Roches Stores, Superquinn, Interlink couriers and Fast Track, who helped with distributing the chocolates.

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

Your support makes MDI a stronger organisation.