Company registered name: Muscular Dystrophy Society of Ireland Ltd.
Company registered office: 75 Lucan Road, Chapelizod, Dublin, D20 DR77
Country of registration: Ireland - 60460
Directors:
Garry Toner
Helen McDonnell (Resigned 5th February 2018)
Hazel Bridcut
Ephraim Purcell
John Roche
Grace Greene
Tom Nolan (Appointed 23rd June 2018, Resigned 24th July 2018)
Anne Horan (Appointed 23rd June 2018, Resigned 10th August 2018)
Kenneth Rowan (Co-opted 13th August 2018)

Registered Charities No.: 20012038
Charity CHY Number: 6489
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FOREWORD

Welcome to another MDI Annual Report. It is the time of year to look back at the achievements of the past year for Muscular Dystrophy Ireland.

This has been another busy and exciting year for the organisation. MDI's goal has been and always will be to increase awareness of muscular dystrophy and to enhance the support services which it supplies nationally.

I would like to take this opportunity to thank all the Health Service Executive areas who continue to provide financial support. I would also like to express my thanks and appreciation to all the people who raised funds for the organisation, their support is invaluable.

This is an ideal opportunity to express my thanks to Dr John Roche, National Chairperson, and the members of the Board who give so freely of their time and expertise. All those members and friends who give of their time for Fundraising, Research, Trust Fund and Memorial Day Committees deserve our appreciation for their wonderful work. Thanks also to all the staff for their hard and dedicated work over the last twelve months.

MDI is a unique organisation because of its member focus and through the process of the Strategic Plan and its implementation, and with the help of our dedicated staff and the ongoing support of you all, we will continue to keep the members at the heart of what we do.
Dear Members and Friends of MDI,

2018, although not without its challenges, has been another positive year for MDI. Once more our membership has increased to an all-time high. Again, it is to the credit of our dedicated staff that despite changes and difficulties during the year, they continue to provide core services to our members.

The permanent CEO position was advertised externally in November 2018 and, following a rigorous recruitment process, Ms Elaine McDonnell was confirmed as our permanent CEO. Building on the foundations laid from the beginning of 2018, with Elaine’s permanent appointment, MDI will continue its work as a member-led organisation that listens to the voice of our members and strives to meet the needs of every individual who needs our support. We wish her every success in her role during this exciting time for MDI.

We continue to be very fortunate to receive our core funding from the HSE, but the resources we receive from the fundraising efforts of our members and friends allow us to put services in place and plan activities which we otherwise would not be able to do. The "Big Ireland Quiz", our new fundraising venture organised in conjunction with the Irish Quiz Organisation, culminated in its first Grand Final in January 2018 and was a welcome addition to our regular fundraising efforts that took place in 2018.

Caomhie Forde’s Variety Concert in Cork and the launch of "The Long Lost Short Stories of Gearoid P. Mannion" at the Clifden Arts Festival showed once again the huge support and love MDI members receive from their siblings and communities, as did the many more events throughout the year which are too numerous to mention. We cannot emphasise strongly enough how important funds raised by our supporters are to the organisation and our grateful thanks go out to staff, members, volunteers and friends who give so generously of their time, effort and money for MDI.

On 20th July 2018, MDI hosted a "Remembrance Day" event in Chapelizod, Dublin to unveil two plaques – one to honour and remember our former Chief Executive Officer (CEO), Joe T Mooney, who passed away in September 2015 and the other to remember all members and friends of MDI who have passed before us. We would like to extend our deepest sympathies to
the families and friends of passed members and indeed to all bereaved members of MDI over the years, and in 2018 in particular.

This is an exciting time in terms of advances in research and treatments for muscular dystrophies and MDI continues to support various projects from the MDI research fund through the direct funding and co-funding of various projects. Patient Advocacy and Influencing Policy has become an increasing part of our Information Service. Much of this advocacy has been focused on emerging treatments such as Translarna for Duchenne Muscular Dystrophy and Spinraza for SMA. One key area for development and research is the creation of an Irish Neuromuscular Disease (NMD) Registry. Given Ireland’s size, access to clinical trials for small groups is extremely difficult so it is hoped that the creation of a dedicated registry may improve access for Irish patients in the future. This will be an interesting area to explore in the coming months.

Our Home from Home apartment continues to be a very welcome facility available to our members and others. 2018 has been the busiest year yet with the number of guests accommodated up by 17% on 2017. With the tireless efforts of our Facilities Manager Owen and Caretaker Damien, improvements to the apartment were carried out throughout the year, greatly enhancing the quality of experience for our guests and this will continue in 2019.

To all our donors and sponsors, MDI would like to express our sincere gratitude for all your support in making our Home from Home into a world class facility.

Our Family Support and Youth Respite Workers continue to provide valuable support to families and young people living with Muscular Dystrophy. New ventures included MDI’s first Sibling Support Workshop which was a great success. The respite support services continue to provide families

with much needed help, while our Summer Camp programme provided 65 members and their families with important respite breaks.

Work on the Strategic Plan continued apace in 2018. Quality Matters conducted a member survey, several member meetings and staff-board workshops. Work also progressed on drafting a new Constitution for the organisation. Our Governance structures continue to be developed towards full compliance with the new Charities Governance Code.

I would like to extend my thanks to the members of the Executive and Council who have worked tirelessly all year. I would like to express my sincere gratitude to Mr Tom Nolan who continued as Interim CEO into early 2018 and for his valuable role on the Board from February until the end of July, overseeing the smooth handover to myself in August 2018. A special mention goes to Ms Anne Horan who joined the Executive at the AGM but had to subsequently retire from the role. Thanks to Ms Grace Greene for serving as Chairperson until the AGM. Sincere thanks also to Mr Garry Toner who has served as Vice-chairperson since August 2018.

I would like to express my sincere gratitude to all the staff of MDI who, as always, exceed what is required in the performance of their duties. I would like to include in this members of staff who are no longer with the organisation and thank them for their contribution.

MDI would not be the organisation it is without the commitment and support of volunteers and branches. Finally, to you, the members of MDI, thank you for your continued dedication and support.

Go raibh maith agaibh go léir.
**INTRODUCTION**

Muscular Dystrophy Society of Ireland Ltd. (MDI) is a voluntary organisation, which was founded in 1972 and incorporated in 1977 by a small group of people in the west of Ireland to support families who had a member with muscular dystrophy.

MDI supports people who have muscular dystrophy and related neuromuscular conditions and their families. These conditions are characterised by the progressive weakening and wasting of the muscles. They 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 some families who have more than one member with the condition.

There is no cure for muscular dystrophy but there have been huge advances in improving the quality of life for people with the condition, and while increased efforts are being made around the world to develop new treatments.

**Breakdown of Members with MD by Type**

![Chart showing breakdown of members with MD by type]

**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.
MDI supports people who have muscular dystrophy and related neuromuscular conditions and their families.

MDI's membership has been increasing every year and we now have 759 individuals with neuromuscular conditions registered as members. MDI also supports the families of people with neuromuscular conditions, including parents, carers and siblings, and provides support and information to healthcare and educational professionals. Our network of support extends to almost 4500 people, and is delivered by our team of staff which covers regional areas in the North East, North West, West, Mid West, South, South East, Midlands, and Dublin.
MDI IMPACT SUMMARY 2018

• 75 Members supported on Respite Camps & Breaks, benefitting approx. 230 more Family Members / Carers
• 813 Youth Respite Visits & Activities
• 300+ Requests for information
• 821 guests accommodated in our Home from Home apartment
• 700+ members supported by our family support service
• 2000+ Member/Case Support Interactions
• 1,470 Transport Journeys Provided to 2,121 Passengers
• 13,374 hours of Personal Assistance provided
• €94,592.13 raised through MDI’s Fundraising activities

MDI INCOME AND EXPENDITURE

Income by Origin 2018

- Donations Fundraising: 3%
- Subscriptions: 0.2%
- Grants and Contract Income: 16%
- Other income: 0.4%
- Investment income: 81%

Resources Expended 2018

- Fundraising Costs: 19%
- Respite Service: 28%
- Family Support Services: 14%
- Youth Services: 13%
- Transport: 4%
- Information: 4%
- Support Costs: 4%
- Other costs: 6%
- Governance: 3%
A key function of MDI is to provide accurate and relevant information to people with neuromuscular conditions, their families, healthcare and education professionals and the general public. Requests range from information about MDI Services to Entitlements and practical supports. MDI's Information Officer is the first point of contact for persons new to the organisation following a diagnosis of a neuromuscular condition. The MDI Information Officer is based in the Head Office in Dublin and provides a nationwide service. In 2018 MDI responded to over 300 individual requests for information.

Advocacy is an important function of MDI. This is done on a local level where MDI staff may support members to help them access new services, or contribute to Local projects aimed at improving the lives of people with disabilities. On a National Level, MDI works both independently and with other organisations to campaign for improved conditions for people with Muscular Dystrophy, and people with all types of disabilities, across Ireland.

We focus in particular on issues of Independent Living, Specialist Health Services, and New Medical Treatments.

On 7 March 2018, the Irish Government passed a motion to ratify the United Nations Convention on the Rights for Persons with Disabilities (UNCRPD), therefore agreeing that it will be bound by the terms and obligations contained in the treaty. The guiding principles of the Convention include: respect, non-discrimination, equality and the full and effective participation of people with disabilities in society. The UNCRPD is made up of 50 separate articles covering a wide range of areas including:

- Health
- Education
- Employment
- Access to justice
- Liberty and personal security
- Independent living
- Access to information.

MDI will continue to advocate to ensure that the UNCRPD is implemented thoroughly and effectively, and hopes the declaration will lead to significant improvements to the lives of people with disabilities in Ireland.
COMMUNICATIONS

Newsletter

The MDI News Update is a newsletter for the members of MDI and includes articles about issues of interest to people affected by the condition, including research updates, articles on entitlements and holidays, photographs and reports on youth clubs and MDI events such as conferences and fundraising events. Three high quality colour editions of the newsletter were distributed to Members and supporters of MDI via post or email.

Website

The MDI website wwwmdi.ie also has a range of information about muscular dystrophy, research, MDI services and events, and fundraising activities. All newsletters, annual reports and conference reports are available on the website to download.

MDI Website Visitor Statistics 2018

Social Media

In 2018, MDI managed two primary Social Media accounts on Facebook and Twitter, respectively. Social Media platforms continue to play a crucial role in supporting MDI’s information and communications activities, enabling members, individuals, and other groups to interact with us more effectively and efficiently.

Our Facebook page reached over 6,000 Likes/Follows and recorded over 24,500 User engagements.

On Twitter, our number of Followers increased by 19 %, and MDI Tweets recorded 64,054 Impressions in 2018.
MDI’s Youth workers work directly with younger members and their families around the country. Through the Youth service, members firstly get to know their youth worker and are then given the opportunity to take part in the many activities organised. These activities include home visits, social outings, youth clubs, Easter and summer camps and hospital respite.

Youth workers support, encourage and enable young members to play an active part in their communities. Through the youth clubs, social outings and camps, members have an opportunity to get together, to make friends and maintain friendships already made. The peer support that is both given and received is invaluable.

The supports offered to our members through the youth service also have a beneficial impact on parents and siblings, giving them a break and much needed time to themselves.

The youth respite team would like to thank all the members for their participation over the last year.

**Youth Respite Activity Highlights 2018**

**Film Camp**

An amazing week of fun, games, imagination, creativity and friendship took place in August at a film making summer camp for young MDI members. The event which took in Cork, comprised of young MDI members who were kept very busy filming, directing, doing make-up, editing, as well as coming up with a plot for a film. There were killer clowns, princesses, soldiers, ghosts, security guards, and Oompa-loompas... as well as a chocolate factory and lots & lots of chocolate!!!! The film was shown at a special premier screening - the first of many for our budding film stars!
Confidence Building

In October, 9 MDI members and siblings attended a confidence building workshop in our head office, which was facilitated by Maria Lynch from Motivated Joyful Living. Members were encouraged to participate in confidence building therapeutic activities which included speaking about insecurities and identifying what they could do to overcome these insecurities. They were given the tools to help improve their self-esteem and confidence by communicating effectively with others. Through a series of exercises, they highlighted and focused on their positive qualities. This was one of the biggest stepping stones towards confidence building.

Here is what one of our members had to say: “It was really good and it helped me understand myself a bit more, my feelings and how I react to things. It is making my life a lot easier in understanding myself.” - Liam

Siblings Days

In 2018, MDI began to develop a sibling support programme to help create a safe space for siblings of members to connect and express their feelings, as well as build friendships and gain support from their peers. Two events were piloted, one in April and one in August, with activities including Drama Therapy, Roll n’ Bowl, Cinema and Sports. Both events were very successful with positive feedback received from everyone who attended. Comments included: “Good, Educational”, “Amazingist day! It was so cool and good activities”, “Best Day Ever!”, “Great, Amazing, loved it!”, and “Today was great because I finally got to do something I could do. My brother is in a wheelchair so we always have to do something he can do but today we could do something I wanted to do”.
MDI continued to deliver the Respite Holiday Camp programme in 2018, with six camps held at the IHCPT Centre in Clarinbridge, Galway. In total 65 members participated in the respite holiday programme during 2018, engaging in activities such as visiting the Salthill Aquarium, dogs race night, table quizzes, treasure hunts, arts & crafts, shopping, cinema, fishing, bowling, pizza making, movie making, murder mystery parties, live in-house music, shopping, spa days and much more!

Members were also able to avail of the MDI Home From Home apartment for shorter respite breaks facilitated by MDI throughout the year.

The respite holiday programme provides an invaluable service to members and families by providing a respite break to parents, partners & Siblings, and carers. The friendships created and maintained through camp between members is both heart-warming and invaluable and throughout the year the youth service is key in helping to maintain these friendships between members from throughout the country through the various activities and outings organized.
Role of the Family Support Team

The role of the Family Support Team is to provide a wide range of information and support to members, their extended family and carers.

The team offer information, emotional support and other support or assistance requested by members under the following categories where possible:

- Health Issues
- Education Matters
- Employment / Unemployment
- Entitlements
- Housing
- Counselling Referral
- Advocacy
- Relationship Building
- Active Listening Service
- Practical and Emotional Support
- Accompany members to hospital appointments
- Visit members in hospital
- Liaise with all other health care professionals and the HSE

- Liaise with schools and the Department of Education
- Support Groups and Social Groups / Outings
- Bereavement Support
- Peer Supervision
- They will also deliver presentations to schools, disability groups and other health care professionals involved in the lives of people living with neuromuscular conditions in helping to promote awareness.
The respite service is an essential support for people living with muscular dystrophy and their families. A major aim of the organisation is to help people to live independent lives and the respite service empowers our members to live the life of their choosing.

MDI Respite Services are categorised as follows:
1. MDI Youth Respite
2. MDI Emergency Respite
3. MDI PA Respite

**MDI Definition of Respite**

Respite care is short-term care that enables a family to take a break from the daily caring role. Respite care can occur in the 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 resources available. 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 health and emotional wellbeing.

MDI provided 13374 Personal Assistance Hours in 2018. There was an increase in the number of members receiving respite support services. However, the total number of hours provided decreased following the completion of a number of respite support services through which MDI had facilitated the delivery of members’ personal assistant service.

**Personal Assistant and in-home respite provided in 2018:**

- 13374 hours provided in 2018
- 12,290 hours provided by MDI PAs
- 1084 hours through external agencies (IWA, CIL, Bluebird, Home Instead etc.)
- 38 members received a personal assistant or in-home respite support
**TRANSPORT AND EQUIPMENT**

MDI has a fleet of eleven specially converted minibuses that cover the whole country. The majority of these buses are used by the Youth Respite Workers as part of their daily work with our younger members. In areas where there is no dedicated driver, we use third party providers to carry out services on our behalf. The transport service includes transporting members to and from hospital and clinic appointments, social outings and respite care, and also delivering MDI loan equipment such as hoists and wheelchairs to hotels and members’ homes.

In 2018, there were two dedicated drivers who provided a transport service to members with a total of 1,470 journeys undertaken providing the service to 2,121 passengers.

The transport service has an excellent safety record and all staff using MDI vehicles take part in continuous GLUAIS training. A Fleet Co-ordinator is in place to ensure all buses are NCT compliant and undergo frequent servicing. MDIs transport fleet ranges between 8 and 16 years old. In 2018 we continued to develop our vehicle replacement programme to ensure that MDI can continue to provide this vital service into the future.

As well as providing a dedicated transport service to our members, MDI also have a range of mobility aids and appliances that are available on loan to members on a short term basis. It is recognised that wheelchairs, hoists, shower chairs and other equipment are central to many of our members’ needs. MDI strives to provide essential aids for members who require such equipment in emergency situations.
Guests

2018 has been the busiest year to date for MDI at our Home from Home Apartment. During 2018 we provided accommodation for 821 guests from a total of 439 bookings.

The apartment continues to offer many of our guests the opportunity to experience Independent Living by taking a short break outside the walls of institutional living, or their first steps away from living at home. This service has been appreciated by the organizations which have regularly used the apartment for respite during the year. Some of the groups still enjoying the facilities are Cheshire Home, Enable Ireland, Ataxia Ireland, St. John of God’s and the Brothers of Charity.

The feedback we received from our clients is crucial in regards to how we endeavour to meet their needs as service users in the future.

The international visitors have come from many different variety of countries which have included France, UK, Germany, USA and Denmark. Their feedback has been extremely positive and it is always vital to have an international perspective on some of the services we are providing.

Renovations

With the assistance of funding from Monkstown Hospital Foundation, Orlaith Humphrey’s Fund, AVIVA Community Fund and SMBC Capital Aviation we completed a number of upgrades to the interior of the apartment. These included security cameras system throughout the premises, a new Jacuzzi bath in room 3, Geberit Aqua Clean 8000 Toilet in bathroom 2, refurbishment of all the profile beds and service of all ceiling hoists. Also the apartment was given a full repainting throughout and this work was all completed in the first quarter of 2018.

Towards the end of 2018 we received the kind donation from United Hardware Ltd of 200 sq. meters of high quality laminated flooring. This flooring will go towards replacing the current carpet tiles which are becoming worn out and are in much need of replacement.
AGM and National Conference 2018

On Saturday the 23rd of June, MDI held our annual general meeting in the Midlands Park Hotel, Portlaoise. The morning began with the business of the day, the AGM itself. The Annual Report and Audited Accounts for the year 2017 were presented to the meeting. There were no matters arising. Both reports (and previous years reports) can be viewed on the MDI website - see: www mdi.ie/mdi-annual-reports-and-audited-accounts.html. The elected Board of Directors for the current year were as follows:

Chairperson: Tom Nolan
Vice Chairperson: John Roche
Secretary: Hazel Bridcut
Treasurer: Ephraim Purcell
Board Members: Grace Greene, Garry Toner, Anne Horan

After the business of the AGM, our first guest speaker, Mr Tom Walsh from Citizens Information gave us a very informative talk on the Citizens Information Board and the various free services they provide. This was a very interactive session, with Members offering lots of good advice to each other in relation to entitlements and services.

After lunch, our Information Officer gave an update on MDI’s Research Fund in 2017. This included updates on the projects funded directly and co-funded with other organisations. The next step agreed by the committee will be the development of a new Neuromuscular Registry which will be of benefit to all members.

Finally, Caroline Gardner from Quality Matters spoke to members about MDI’s strategic plan process and introduced a survey for members to complete.

Thank you to all members who attended the AGM and to our speakers on the day.
RESEARCH

One of MDI’s aims is to fund and support research relating to muscular dystrophy. This includes biomedical research, which looks at what happens in the body when someone has muscular dystrophy, or identifies potential therapies. It also includes social research, which examines issues like education and quality of life.

In 2018 MDI continued to fund medical research through the direct funding of a project in Maynooth University. Two further projects are co-funded via the Collagen VI Alliance in Newcastle University and the Rizzoli Orthopaedic Institute, Bologna. Work continued on the two research projects co-funded by MDI and The Health Research Board / Medical Research Charities Group Joint Funding Scheme (2017). This research was conducted in Maynooth University and Oxford University. Both projects received 50% funding from the HRB and 50% funding from MDI in 2018.

In early 2018 MDI conducted a review of patient registries with the short to medium term view of setting up a Neuromuscular Disease Registry for Ireland which could become self-sustainable in the long run. One of the main reasons for a registry is to identify potential candidates for clinical trials. The outcome of the MDI review was that the Irish NMD Registry should be modelled on the New Zealand Registry. The curator of the New Zealand registry, Ms M J Rodrigues, visited MDI in early June 2018 and made a short presentation to the MDI Research Committee. Investigation into the setting up an Irish NMD Registry is ongoing.

#SPINRAZANOW

It is currently an exciting time for muscular dystrophy with the emergence of new treatments and a high level of innovation in an area of high unmet needs. But the availability of these therapies in Ireland brings challenges particularly with regard to approval and reimbursement. Over the past number of years, MDI has been campaigning and working with policy makers in an attempt to gain access to much needed new therapies.

In August, families of people with Spinal Muscular Atrophy formed SMA Ireland in order to campaign for the reimbursement of the SMA therapy Spinraza. With support from MDI, SMA Ireland created the #SpinrazaNow campaign which successfully brought both public and political attention to the need for approval of the drug’s reimbursement.

Great strides were made in 2018, and it is hoped that SMA Ireland will go from strength to strength in 2019 and see a successful outcome for members and people with SMA across Ireland.
ICP NMD

Throughout 2018, MDI has contributed to the HSE’s Integrated Care Pathway for children with Neuromuscular Disorders.

This pathway has been co-designed by parents, young people and healthcare professionals and sets standards for what is required to achieve a high quality, child and family centred service for children and young people with a neuromuscular disorder. This will hopefully lead to the establishment of a standardised delivery of care to children with Muscular Dystrophy and other neuromuscular conditions from diagnosis through to transition into adult services.

The ICP-NMD project will deliver a range of practical resources to help families themselves, and people delivering services and supports, with information that is clear, accessible and child & family centred. This is expected to come to fruition in 2019.

STRIVE

In 2018, MDI was awarded $25,000 from PTC Pharmaceuticals, to deliver a new and exciting project for members with Duchenne Muscular Dystrophy.

PTC is the manufacturer of Translarna, a drug treatment for Duchenne Muscular Dystrophy. In addition to its medical research work, PTC runs a grant awards programme called STRIVE. Through STRIVE, Patient Advocacy Groups, who deliver supports and services to people with Duchenne, can apply for funding to deliver innovative new projects for their members.

The grant awarded to MDI will allow us to pilot a new ‘Independence and Engagement Project’ in 2019, which will focus on helping members with Duchenne to develop their own self-confidence and independence, as well provide them with a platform to engage new interests and opportunities.

We hope to be able to open the Project to all members and, if successful, secure additional funding that will allow us continue it into the future.

Powerchair Football

MDI was again proud to support Irish Powerchair Football in 2018 and our members who play this exciting and rapidly growing sport. Nationally, a number of one off support services were provided to members to help them attend training sessions or match days, while we also supported ten players and their clubs who travelled to the EPFA European Champions Cup in Denmark in October 2018.

Having helped to kick-start the sport in Ireland in 2003, MDI is delighted to see the sport go from strength to strength and will continue to play a role supporting members to participate at all levels.

Operation Enable

Operation Enable is a multi-agency awareness campaign created to remind motorists to respect disabled parking bays, and permit holders to respect the conditions attached to their permits. This new initiative will benefit thousands of disabled motorists and passengers nationwide (many of whom are MDI members) and we want to acknowledge MDI member Jimmy Murray for his role in inspiring the creation of Operation Enable, through his engagement with members of the public and An Garda Síochána about...
these issues. Jimmy, who currently works as part-time receptionist in MDI’s Head Office, has been involved with MDI for over 35 years and is a former Chairperson, Secretary and Board member of MDI. Some years back, Jimmy set up a Facebook page entitled “Disabled and Limited Mobility Parking Bays” to help highlight the abuse of and illegal parking by non-disabled motorists in disabled parking bays throughout the Republic of Ireland. This Facebook page now has over 5,200 followers on which individuals can post photos of illegally parked cars.

**NMC UK**

In November MDI welcomed Matthew Lanham, Chief Executive of a UK charity called the Neuromuscular Centre (NMC), to our Head Office and Home From Home Apartment. NMC were founded in 1990 to provide physio treatment, support, training opportunities and employment for people living with muscular dystrophy and associated neuromuscular conditions. It was invaluable to be able to share experiences of running very similar sized charities on opposite sides of the Irish Sea. Matthew was particularly keen to learn about the Home From Home Apartment and plans to develop a similar project with NMC. We look forward to keeping close links for learning and collaboration in the future with the view to improving the work of our organisations and benefits to our members.

**MDI Board Room**

During 2018 MDI House and its Training Room/Boardroom was used by a wide range of organizations and local community groups.

The Boardroom has been used by a number of different organizations for their management meetings and community activities. This allows them to have a facility that meets their needs and provides access for all their membership. It also promotes our organization in the community and creates a social inclusion for all. The groups that have used our building during 2018 are diverse and have included Lucan Disability Action Group, Post-Polio Support Group, Disabled Drivers Association, Ataxia Foundation Ireland and many others.

Throughout 2018, the Boardroom was promoted as a training facility. This has created a large increase in numbers of training organizations using the building for training purposes. It also has generated an additional income for MDI which has gone toward our vital services. We have been particularly fortunate in our relationship with Ballyfermot Senior College and Clondalkin College of Further Education to which we provide Manual Handling training for all their Social Care students. Going forward in to 2019 it is anticipated that we will keep these relationships ongoing and develop our training facility further.
On Friday, 20th July, 2018, MDI hosted a “Remembrance Day” event at our premises in Chapelizod, Dublin. The purpose of this event was to unveil two plaques – one to honour and remember MDI’s former Chief Executive Officer (CEO), Joe T Mooney, who passed away in September 2015 and the other to remember all members and friends of MDI who have passed before us.

The audience on the day consisted of MDI Staff and Board Members, along with the family and friends of five members of MDI who passed away in recent times and who were significant players in the initial development, growth and expansion of MDI. These members were: Joe T Mooney, Florence Dougall, Martin Naughton, Judy Windle and Ursula Hagerty.

The programme for the day started at around 3.30pm, when invited guests began to arrive prior to the arrival of the Lord Mayor of Dublin Cllr. Niall Ring and the current Miss Ireland Lauren McDonagh, who were the main guest speakers on the day.

A light mist and a humid atmosphere descended amongst everyone present and brought with it a warm and sometimes an emotional presence as members, friends and families gathered and shared memories and stories, prior to proceedings.

This article was first published in the MDI News Update Autumn Edition 2018

Hubert McCormack
Lauren McDonagh was the first of our guest speakers to arrive on the day. Lauren, who is the current Miss Ireland, has a personal connection with MDI as her brother Darren had Duchenne muscular dystrophy and sadly passed away in 2008. Our event coordinator for the day, Owen Collumb, introduced Lauren to everyone present, many of whom she knew already because of her involvement some months earlier in helping MDI to promote our awareness campaign last February.

At 4.00pm, the Lord Mayor of Dublin Cllr. Niall Ring arrived and was greeted by MDI’s CEO, Elaine McDonnell. Elaine spent the next while introducing the Lord Mayor to everyone present before proceedings began. She then officially welcomed everyone before inviting Hubert McCormack to officiate for the unveiling of the first plaque in memory of Joe T. I commented on my friendship with Joe T of almost 30 years and referred to his outstanding achievements before introducing his wife Aisling who spoke on behalf of the Mooney family, most of whom were present. Aisling thanked MDI for acknowledging the work of Joe T and indeed, for its value in seeing the need to have a permanent memorial to honour all members of MDI, whom she referred to as one big family who liked to party!

Elaine then introduced the Lord Mayor who firstly picked up on Aisling’s comment about “parties” and invited everyone present to the Mansion House in the coming months to celebrate our achievements and to prove to him that we really did know how to party! And on a more serious note, he commented on Joe T’s many achievements, with particular reference to our fabulous office space and Home from Home Apartment, which is undoubtedly one of Joe T’s lasting legacies. The Lord Mayor then invited Joe T’s wife Aisling to assist him with the unveiling of the plaque to honour Joe T and then allowed for photo opportunities with him and Joe’s family.

Continues over...
Everyone then congregated in the back garden for the unveiling of a second plaque to remember all passed members of MDI. Prior to the unveiling of this plaque our CEO Elaine invited me to once again lead off proceedings. I spoke of the significance of MDI having this space of remembrance, which was primarily funded by donations in memory of Florence Dougal, whose family were present. I commented on how elegant this fountain and feature looked and expressed what I believed would have been Joe T’s and Florence’s sentiments and sensed their nod of approval.

As this space is in memory of all passed members of MDI, I also felt it necessary to mention three other former members who passed away in recent times who were equally as instrumental in helping to bring MDI to where we are today. They were: Martin Naughton, Judy Windle and Usula Hagerty, who were all represented on the day by members from their respective families. Martin, Judy and Ursula (whom I all knew personally) had served at every level within MDI for most of their lifetime and they were all equally as passionate for the growth of MDI and disability rights in general.

Elaine then invited the current Miss Ireland, Lauren McDonagh to say a few words. Lauren spoke about her brother Darren and of her childhood memories of MDI and attending youth clubs and camps. She expressed her delight at being here today and the significance of what it meant to her and her family to have such a memorial space in memory of passed members.

Before Elaine invited the Lord Mayor to unveil the second plaque, she called for a minute’s silence in memory of all passed members of MDI. She then invited Florence’s sister Jaqui and the Lord Mayor to unveil the plaque in memory of all members, after which there were more photo opportunities for members with the Lord Mayor.

Once all official proceedings were over, light refreshments and finger food were served and everyone had an opportunity to mingle, share stories and remember members no longer with us in a happy, yet sometimes emotional, way.

For me personally, this day was about remembering, reflecting, acknowledging and celebrating. It was about being proud of what MDI has achieved over the last 46 years (since our early beginnings in 1972) and ensuring that all of which we have achieved will continue to grow and expand. I believe that we owe this to the vision and to the memory of our members and friends who have gone before us. I am confident that everyone present on the day felt likewise.

Finally, I would like to thank everyone at MDI for realising the need to arrange this Remembrance Day and for making it so special. It meant a lot to me and indeed to everyone present.
MDI host a variety of national and regional fundraising events throughout the year to fund the respite support service, medical research, as well as the 'Home from Home' Apartment.

Many of the national and regional fundraising events continued to run with great success. As always the tireless commitment of MDI’s members, friends, supporters and volunteers is very much appreciated and we extend our sincere thanks to everyone who made fundraising possible.

MDI would like to thank all the people who kindly made financial contributions towards the respite support services, medical research and the 'Home from Home' apartment in 2018.

All donations great and small are sincerely appreciated and are very important to ensuring continuity of the support services. Your efforts have helped to raise a total amount of €94,592.13 for MDI in 2018.

**Fundraising Highlights 2018**

1. Harley Davidson Annual Draw €23,221
2. Mizen to Malin Cycle €6,768.02
3. Tesco Appeal Flag Day €5,864.64
4. LOVE MDI Campaign Chocolates €3,382.20
5. Mini Marathons €7,166.46
6. Trad Dash Ashbourne €7,220
7. Gearóid P. Mannion Book €5,500+
8. C. Forde Variety Concert €5000

**Mini Marathons**

Approx. 50 ladies took part in the Dublin and Cork Ladies Mini Marathons in June and September of 2018 and through sponsorship collection the events raised €7,166.46. Each year MDI is continuously seeking ladies to take part and raise valuable funds for the respite support services.

**Tesco Collection Day**

MDI held the 6th Annual Collection Appeal across Tesco Stores nationwide on the 4th May. MDI is extremely appreciative to Tesco for the opportunity to raise money and increase awareness. The day was very successful and raised €5864.64. MDI were in 11 stores and would like to thank our volunteers and Tesco Ireland for their continued support.
Mizen to Malin Cycle
Between 26th July to the 29th July, 14 cyclists from the company "Arup" cycled from Mizen Head to Malin Head for Muscular Dystrophy Ireland and raised the tremendous amount of €6,768.02.
En route, the group stayed at the following places: Ballyhoura Hostel, Kilfinane, Limerick. Esker Riada Apartments in Athlone ad the Belmore Court Motel in Enniskillen. The group of cyclists covered most of their own expenses in order to take part in the cycle. Well done to you all for achieving an amazing feat of cycling the length of Ireland and thank you for your support.

Caoimhe Forde’s Variety Concert
On Friday 13th April last, Caoimhe Forde from Cork held a Variety Concert in memory of her brother Ciaran who passed away over three years ago. The night was an amazing success and raised €5,000 for MDI. The concert featured a host of well know Irish acts including comedian and author Colm O’Regan. Special Guests also included Stephanie Rainey and Gary Keane, Conor O’Donohoe and David Whelan of Dublin band Wild Youth and their manager Niall Morris.
The Long Lost Short Stories of Gearóid P. Mannion

Hidden in a cupboard under the sink for over a quarter of a century lay a collection of essays long forgotten. Enter the world of a precocious teenager growing up in 1980’s rural Ireland. Gearóid P. Mannion passed away at 21 but his legacy lives on in these funny, heartfelt, warm essays written when he was a teenager.

In 2018, Gearóid’s sisters Karen and Sinead published their brother’s stories, with proceeds of the book going to MDI. Over €5,500 has been raised to date.

Bikefest

Each year MDI host a national draw to win a magnificent Harley Davidson Motorcycle. The draw is held at The motorbike event called ‘Ireland Bikefest’ which takes place at the Gleneagles Hotel, Killarney, Co Kerry.

MDI continue to be the chosen charity for Bikefest and it was the 12th year for MDI to be associated with the event. The Harley Davidson national draw goes from strength to strength each year. The 2018 Ireland Bikefest took place from the 1st to 4th June and the draw raised €23,304.93. MDI would like to thank the staff and management of the Gleneagles Hotel in Killarney for organising this fantastic event and for continuing to support MDI. Also thank you and much appreciation for the outstanding work of everyone who assisted in selling the tickets and all the MDI volunteers who distributed them on our behalf, sold and bought tickets, helping to make this event a great success.
CONTACT DETAILS

Company registered name  Muscular Dystrophy Society of Ireland Ltd.
Company registered office  75 Lucan Road, Chapelizod, Dublin 20 Eircode D20 DR77
Country of registration  Ireland
Company Number  60460
Registered Charity Number  20012038
CHY Number  6489

National Executive 2018
John Roche  National Chairperson
Garry Toner  Vice Chairperson
Hazel Bridcut  Company Secretary
Ephraim Purcell  Treasurer
Grace Greene  Executive Member
Kenneth Rowan  Executive Member

Chief Executive Officer  Elaine McDonnell

Head Office
Muscular Dystrophy Ireland
75 Lucan Road, Chapelizod, Dublin 20
Eircode D20 DR77
Tel: 01 6236414 / 6236415
Freephone: 1800 245300 • Fax: 01 6208663
Email: info@mdi.ie • Website: www mdi.ie

MDI Regional Offices

MDI Midlands Office
c/o Mullingar Employment Action Group,
The Enterprise Centre, Bishopsgate Street,
Mullingar, Co. Westmeath
Tel: 057 934 6795

MDI Galway Office
Galway Technology Park
Tara Rock, Parkmore, Galway
Tel: 091 395 497

MDI North West Office
c/o MS Society
28 Slieve Sneacht Close, Glencar,
Letterkenny, Co Donegal
Tel: 086 389 9279

MDI North East Office
North Eastern Area Health Board
Climber Hall, Kells, Co. Meath
Tel: 046 928 0026

MDI Cork Office
c/o Irish Guide Dogs for the Blind
National HQ & Training Centre
Model Farm Rd, Cork
Tel: 021 421 4052

MDI South East Office
c/o Irish Wheelchair Association
Kilkenny Rd,
Mortarstown Upper, Co. Carlow
Tel: 059 914 0983

MDI Mid-West Office
c/o Spina Bifida & Hydrocephalus Association
Delta Retail Park, Ballysimon Rd,
Co Limerick

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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 LoveMDI Campaign and other fundraising events.

Thank you to all MDI staff for their hard work throughout 2018, 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, Harley Davidson raffle tickets, Christmas cards, participating in the mini marathon and organising various other events throughout the country.

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