



MDI News Update

Two monthly newsletter - Issue One



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Editorial

Hi,

Welcome to the first issue of the newly structured MDI magazine, which will now be known as the MDI News Update. The idea behind the new format is to bring you updated news on a more regular basis. Therefore, further publications will now consist of a 6-8 page newsletter and will be produced every two months. We also plan to post a copy on our website (www.mdi.ie)

On behalf of MDI, I would like to show appreciation to everyone from the Cork office who was associated with the MDI magazine over the years, in particular, John O'Connell, Paul Butler, Ann and Eileen Wilkins, Anthony O'Dea, Sheila Curran, Peter Towe, Pat Crowley, Claudagh Caulfield, Finbarr O'Riordan, Philip Barry, Maria Lucas and Clare Louise Creedon. To anyone else who I may have forgot to mention - I apologise. Thanks to all for the excellent work carried out over the years.

Inside this issue, among other things, you will find: an article by our new Director, Joe T. Mooney. Joe, who will be known to many of you, took up position last July. Also featured are articles from our recent summer camps, which were held in Lucan and Galway, an interesting item about Neuromuscular Terminology and an article written by Philippa Harpin about Design for Living. Ms. Harpin will be speaking at our forthcoming Annual Conference and AGM which will be held on Saturday 22nd September 2001. Details are also inside. We look forward to seeing you there.

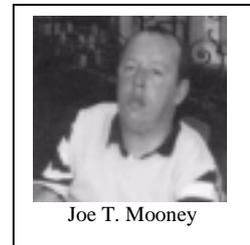
Finally, if you have any articles or suggestions/ideas for the next issue, or details of forthcoming events you would like to publicise, send them to myself or Steven Valentine at the MDI Office. Alternatively, you can email them to info@mdi.ie.

Enjoy!

Hubert McCormack

Meet the New Director!

Hello, Members and Friends of MDI. I would like to take this opportunity to introduce myself. Last July, I was appointed as Director of MDI. I have been connected with MDI for the past 20 years. Originally from Donegal, I first became involved as a branch member of the Donegal Branch of MDI. Then, I moved to Dublin and progressed to National Treasurer of MDI, a position which I held for the last eight years.



Joe T. Mooney

As a person who has muscular dystrophy, I believe I have a good understanding and awareness of the issues and barriers that need to be addressed. I am looking forward to the challenge of this role and have a number of ideas that I believe will benefit MDI and it's members.

Over the coming months I plan to visit all the Branches and meet the members, whom I believe are the heart of MDI. In the meantime, if any member wishes to talk to me, please do not hesitate to contact me at the MDI office on freephone 1800 245 300.

I look forward to working with you all and meeting you soon.

Joe T. Mooney

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SUMMER CAMPS

GALWAY CAMP

28th July -4th August 2001

By Steven Valentine

Eleven members from MDI, myself included, spent one week at Kilcuan Holiday House, Clarenbridge, Co. Galway from 28th July -4th August 2001. We had a great week - here's a summary!

SATURDAY

A Long drive lay ahead for all today. We from the Dublin, Kildare and Wicklow area met at Coleraine House at 1.00pm. On the way we stopped at McDonalds in Athlone. The journey was fine and when we arrived at Kilcuan we were shown around the impressive facilities. Once settled in we went to a hotel for dinner and a few drinks.

SUNDAY

In good weather we visited the Cliff's of Moher which is a great sight to behold and to be recommended to visitors in the area. After dinner we went on to Images Night Club in Gort. While there we met an interesting character to say the least!!



Galway Youth Camp, Clarenbridge, Galway

MONDAY

Today we went shopping and then onto the cinema to see Swordfish at the Ormond in Galway. The film starred John Travolta and everyone seemed to enjoy it. We had dinner at the Menlo Park Hotel and it was very nice.

TUESDAY

On Tuesday we were at the Galway Races and it was a very enjoyable day all round. We arrived at four-o'clock and the sun was shining. There was a great atmosphere and we were all hoping it

was going to be our lucky day, for a few of us this turned out to be true! The big winners were: Colin, Andrew, Barry and Mary-Rose who struck the jackpot at 33-1 in the 6.50 race! Note the author forget the tip-oops.

WEDNESDAY

The fjord beckoned on this bright morning as we headed to Connemara for the day. The weather turned to rain as we got to our destination just in time to meet The Connemara Lady, a boat in case you are wondering. The trip took an hour and half and it was smooth sailing all the way except as we entered the mouth of the Atlantic Ocean. The facilities for wheelchair users were excellent and to be recommended.

We went to the Peacock's Hotel in Maam Cross where we celebrated Desmond's birthday with a surprise cake. Later we all travelled into Galway City to sample the nightlife.

THURSDAY

The week was flying by so we headed to a shopping centre just outside Galway City centre. While we were there a few of us splashed out on two bottles of Champagne to celebrate Tuesday's success at the races. After we had dinner out in Spiddal at the Ceol Na Mara Hotel. Following this we ended up at a night club in Salthill unfortunately the DJ left much to be desired but that is only a personal view. However he was only on for a short time and every one had a great night.

FRIDAY

As usual the smell of a fry up was a good incentive to get up. Later we got ready for the final day so we wanted to make the most of it. Shopping was first on the agenda in the Eyre Square Centre. Splitting up we headed for our favourite shops, in my friends case the sports shops. We gathered in the park to say goodbye to Sammy and Patricia who had helped us and were good fun. Dinner was at the Menlo Park Hotel once more and yet again proved delicious (my steak was mouth watering). After a brief stop for



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champagne at Kilcuan to begin our final evening in the right mood we headed for Images Night Club in Gort. This was a great way to round off a very enjoyable holiday as we danced the night away into the early hours of the morning.

SATURDAY

The morning after the night before was not the most pleasant experience of the holiday for me. However these things happen and it certainly did not detract from a great holiday. We got ready to leave and E-mail addresses and phone numbers were exchanged before we headed home.

We must say a special thanks to those who organised the Camp and gave us the opportunity to have such a good time.

Lucan Youth Camp

2nd-8th July 2001



Jannette Kiely and Pippa at Lucan Youth Camp

From 2nd - 8th July, a group of 22 members between the ages of 11 and 15 participated in this years summer camp in Lucan. Activities for the week, amongst other things, included trips to Dublin Zoo, the Viking Adventure Centre and the National Museum at Collins Barracks as well as music and arts and crafts workshops. Jannette Kiely, from Cork was one of the participants in Lucan who sent us in an article expressing her thanks etc. Jannette writes.....

"I'm writing to tell you that I had a fab time in Dublin. We went to Dublin Zoo, the cinema, bowling to a farm and had a disco. I had a brill time. I would like to say hello to everyone that went to the camp especially the people from Donegal! A big thanks all the helpers, the music people and art teachers. I would like to thank MDI for inviting me and hope to see you all next year".

Jannette Kiely



Lucan Youth Camp - 2001

MDI Vans



Did you know?

MDI has a new minibus that will be unveiled at the AGM on 22nd September 2001. . It is a Volkswagon Caravelle (blue) and was donated by CONTROL AER (a sales and manufacturing company based in Ballyfermot).

Thanks to CONTROL AER, this means that MDI now have 3 bus's, the aforementioned plus another Caravelle (red) and a Nissan Cargo.

These are available for hire to our members. Phone MDI for details and booking.



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Design for Living

This article was taken from Target md. Magazine of the Muscular Dystrophy Campaign, UK. Winter 2000

Philippa Harpin, National Occupational Therapy Advisor, in the UK has published a unique book that will be a vital tool for families affected by muscular dystrophy. She talks to Kate Russell about her **Adaptations Manual** and why she wrote it.

It is estimated that 50% of wheelchair users cannot get in or out of their own homes unaided (this figure rises to 90% for electric wheelchair users). Armed with these incredible figures, Philippa Harpin has written a comprehensive home **Adaptations Manual** for people with disabilities.

The manual outlines how the challenges that come with muscular dystrophy, and day-to-day home life, can be made more convenient, manageable, and rewarding. "Some people know exactly what they need, others are seeking advice," says Phillipa. "When the disability is progressive, as in most types of muscular dystrophy and allied neuromuscular conditions, the future may be uncertain and the people concerned may not be aware of what they are likely to need, or of the solutions that are available.

The **Adaptions Manual** seeks to provide all the necessary information without overlooking or under estimating the emotional upheaval involved with any changes to the family home. For instance, there are chapters on the merits of 'lift v's extension' and 'bath v's shower'. Each argument is designed to empower individuals and make them as independent as possible, The pros and cons of each argument are made with the clarity and precision of a military strategist, yet delivered with compassion.

"The manual, and the discussions within it, are about giving people choices," explains Philippa. "It gives people the opportunity to make their decisions from a base of knowledge, rather than having them forced on them. It takes a lot of courage to say what you need."

Where possible, Philippa encourages the disabled person to take on the role of keyworker. "No one will care more about the adaptations than the recipient." And for many adults with a neuromuscular condition, the project may even give them focus and direction when there is chaos all around. The manual's step-by-step guide to funding applications tells families exactly what is reasonable to ask for, at what stage. Putting the disabled person in a much more informed position when the assessment takes place.

Philippa has put everything into creating the manual. It took two-and-a-half years to write, but has been a lifetime in the making. Nothing has been overlooked in its creation. Even the loose-leaf format with dividers has been chosen to enable anyone who has difficulty in lifting a heavy book to read each chapter separately. "I am anxious to share my experience and I feel I have a responsibility to put it on paper." Says Philippa. She certainly does leave a valuable legacy for the future.

Philippa Harpin, will be coming to Dublin to run a Training Day for Occupational Therapists from all over Ireland on Friday 21st September.

She will also be speaking at the MDI Annual Conference and AGM in the Ashling Hotel, Dublin on Saturday 22nd September.



Simply Stated.....

Neuromuscular Terminology

This article was taken from a recent edition of the MDA Magazine "Quest". We thought it was a very useful article in helping members understand the exact terms used to describe their condition. Very often, this is not explained in "lay mans terms" and can be quite confusing. We hope you find it useful.

Medical terminology can be a confusing morass of words that sound similar but have different meanings - or words that sound different but mean the same thing.

One way to simplify "Medspeak" is to break it into the basic components. In neuromuscular diseases, those components are often Greek root words. Here is a quick glossary to help you understand how the names of various neuromuscular diseases arose, and the differences among them.

Myopathy - From the Greek word *myo*, meaning muscle, and *pathos*, disease or suffering.

Definition: any disease or abnormal condition of voluntary muscle.

Neuropathy - From the Greek word *neuron*, meaning nerve or sinew, and *pathos*, disease or suffering.

Definition: any disease of the nervous system. Amyotrophic lateral sclerosis and spinal muscular atrophy, in which loss of nerve cells prevents muscles from working, are neuropathies, as are diseases in which nerve fibres malfunction, such as Charcot-Marie-Tooth and Dejerine-Sottas disease.

Dystrophy - From the Greek work *dys*, meaning abnormal or faulty, and *trophie*, nourishment.

Definition: a disorder caused by defective "nutrition" or metabolism.

Muscular Dystrophy - This term is actually a misnomer based on the wrong assumption

made many years ago that muscle was being damaged by a lack of nutrients. In modern usage, it refers to a group of genetic myopathies in which a muscle protein is absent, deficient or abnormal.

The disorders classified as "muscular dystrophies" are myopathies in which a genetic defect results in structural damage to the muscle. Other myopathies involve damage to the muscle's contraction apparatus or energy production system.

Atrophy - From the Greek words "A", meaning not, and *trophie*, nourishment.

Definition: a decrease in the size of an organ or tissue (wasting). Common causes of diseases involving muscle atrophy are a lack of nutrients or blood supply or loss of signals from nerve cell.

Spinal Muscular Atrophy - The muscle wasting or atrophy in this genetic disorder results from loss of signals from nerve cells in the spinal cord.

Myasthenia - From *myo*, meaning muscle; a, without; and *sthenos*, strength.

Definition: muscle weakness or lack of strength. Today, "myasthenia" refers specifically to muscle weakness resulting from faulty communication between nerve and muscle at the place where nerve and muscle meet (the neuromuscular junction).

Myotonia (adjective myothonic) - From *myo*, meaning muscle and *tonos*, tone.

Definition: inability to relax muscles after contraction.

Myotonic dystrophy - This genetic disorder involves (but isn't limited to) both myotonia and structural damage to muscles (dystrophy).

Myositis - From the Greek word *myo*, meaning muscle, and the Greek suffix *itis*, meaning inflammation of.

Definition: a inflammation of the muscle, which can result from infection, injury, or attack by the immune system on muscle tissue.



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MDI Receive Generous Gift from Control Aer

Muscular Dystrophy Ireland were recently presented with a very generous donation of a Volkswagen Caravelle, specially adapted for wheelchair use. The Van was donated by CONTROL AER, who took the smart decision to spend the money they would normally spend on corporate gifts for their clients at Christmas, on a gift which would make a real difference to the lives of members of MDI.

The new van is based at our head office at Charmichael Centre in Coleraine House in Dublin 7, and will be used on a constant basis for youth clubs, holidays and other transport needs throughout the year.

Control Aer Ltd is a sales and manufacturing company based in Ballyfermot who supply and manufacture a complete range of ventilation and air conditioning products. It was in view of the enormity of both the development and success of the company which caused them to reflect on how to give back a little.

"Control Aer are delighted to have been able to provide this Caravelle", said John Grainger, Director, Control Aer. "We don't see it as so much to do with charity as redirecting resources to a far more worthwhile, lasting and beneficial use, which will be appreciated for a long time to come. We hope it may be the start of a trend-setting example which in years to come might get up its own momentum in many more such examples".

Judy Windle, Chairperson of the MDI said, *"We were delighted when we heard of Control Aer's fantastic gift. As a charity, we rely heavily on the generosity of others, and so such a donation is wholly appreciated. The new van will be highly valued and kept very busy, bringing added comfort and joy to a huge number of our members".*

€day: Euro Changeover

On 1 January 2002 (€-day), euro notes and coins will begin. There will therefore be a dual circulation period, during which the use of euro notes and coins will be increasing and the use of Irish notes and coins will be decreasing. The mechanism for bringing this period to an end and completing the changeover to euro cash will be to withdraw legal tender status from Irish notes and coins.

Legal tender status will be withdrawn from Irish notes and coins at **midnight on Saturday 9 February 2002**, thus ending the dual circulation period. This will mean that from that date, there will be no obligation to accept payment in Irish notes or coins.

Coin Operated Machines

It is expected that the operators of coin payment machines will aim to have the bulk of their machines converted to accept euro coins by the end of two weeks from €-Day (1 January 2002).



How the changeover can help MDI

It is estimated that there are thousands of pounds worth of Irish coins throughout the country left lying in drawers, jars etc. Why not put them to use rather than leaving them aside by donating them to MDI. We would appreciate any support you can give.

For Sale

97 Fiat Scudo - 1.9 Diesel
50,000 miles - £7,000 ono

Contact: Mary Molloy
at 078 48962



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This years

Conference and AGM

of

Muscular Dystrophy Ireland

will be held in the

**Ashling Hotel, Parkgate St.
Dublin**

on

Saturday 22nd September 2001

Programme

- 10.30a.m. Registration and coffee
- 11.00a.m. Presentation by Ms. Philippa Harpin, National Occupational Therapy Advisor to the MD Campaign of Great Britain.
- 12 noon Presentation by Client Technical Service Department of the Central Remedial Clinic on the situation in Ireland with regard to aids, appliances, grants, information technology and adaptations.
- 12.45p.m. Discussion
- 1.00p.m. Lunch
- 2.30p.m. Presentation by a Geneticist from the National Centre for Medical Genetics, Crumlin, Dublin.
- 3.30p.m. Annual General Meeting of MDI
- 5.00p.m. CLOSE

Our first speaker, Ms. Philippa Harpin will be starting her presentation at 11.00am sharp, so we would appreciate it if everybody attending could arrange to be there on time.

If families wish to bring children with them, please let us know their names and ages in advance so that we can arrange some suitable entertainment for them. Lunch will also be available for the children.

We look forward to seeing you on the day.



We realise it is only September and you probably don't want to be reminded about Christmas!!!!

However, we would like to remind you that Christmas cards are now available from the MDI office in Dublin.

If you are interest in selling some on behalf of MDI, or just wish to buy some for yourself, please contact the office on freephone 1800 245300.

Cards are sold in **packs of 8** assorted designed at **IR£3.20 a pack or €4.00 (Euros)**. Designs will be posted up on our website (www.mdi.ie) shortly.



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New Staff

Here at MDI, we would like to welcome two new members of staff on board.

Hazel Bridcut, known to many members, who has been a member of the Dublin Branch and a dedicated volunteer in our Dublin office for many years has recently taken up a position in accounts.

Also know to many is Helen O'Brien (formally the Information Officer), who was appointed as Family Support Worker for the Eastern region.

We wish both Hazel and Helen well in their new posts.

Did you know?



Liffey Valley and Blanchardstown shopping centre's in Dublin are offering a Scooter loan while you shop to make life easier. You have to have ID with a photo on it and leave your name, address and phone number. There is no charge!

For Sale

Wheelchair accessible Volkswagon Caravelle 99 D. 1.9 Diesel. 26,000 miles. IR£18,000. Phone Joe at the MDI office on 1800 245300 for details



Pictured at a recent barbecue last August hosted by the Midlands Branch of MDI are members Niamh O'Reilly (Longford) and Ashling McElligott (Tullamore). From all accounts, a great day was had by all.

Advertising Space

This newsletter is distributed to our membership of appropriately 500 families nationwide. Future issues will also be posted on our website.

To help defray the cost of this newsletter, we are offering advertisement space to corporate companies. If you are interested in advertising in this space, contact Hubert or Steven at the MDI office on (01) 8721501 or 8723826.