



# MDI News Update



*Two monthly newsletter - Issue seven, September 2002*

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## **Editorial**

Hello again,

Welcome to the latest edition of our newsletter. Sorry it's a little late this time around, but between camps, holidays and preparations for our recent conference and AGM, it's been fairly hectic here - to say the least.

As you are aware, MDI held its Annual Conference and AGM on Saturday 14<sup>th</sup> September in the Tullamore Court Hotel, Co. Offaly. The conference was a great success and was well received by those who attended. There were four guest speakers, all of whom were experts in their respective fields (see page 3 for a summary of their presentations).

Following the Conference the AGM took place and you can read a copy of the Chairperson's Report on page 4. Overall, the day was a great success and enjoyed by all who attended.

Also featured in this issue (on page 2) is an article written by Karen, our Information Officer, on the topic of Duchenne muscular dystrophy and gene therapy, which many of you will find interesting.

Summer is now well and truly over, and so are the MDI camps for this year. You can read articles on the remaining camps for this year on pages 6 and 7.

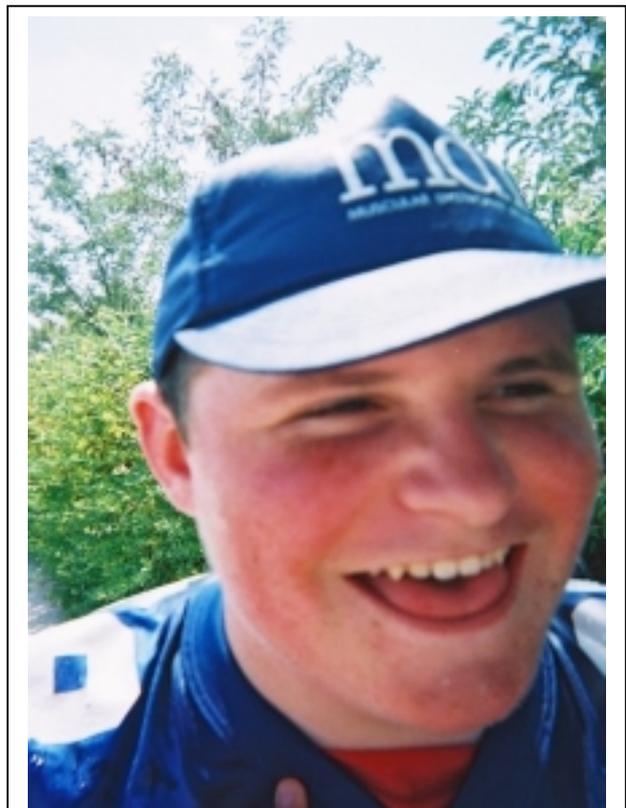
On the subject of holidays, there is also an article on page 8 which was written by MDI member Marian Gilligan from Dublin. Marian describes her recent holiday in Switzerland as "a gem of a holiday" because of the wheelchair access etc.

and she wished to share her experience with fellow members.

Along with news from Cork and Kerry (pages 8 and 9), information on MDI's Respite Service (page 10), and other tippets of information, I'm sure there's something of interest for everyone.

Until next time, happy reading and take care!!

**Hubert McCormack**  
**Editor**



***"The smile that says it all"***  
*MDI Member Daragh Tyrell (Wexford) having a laugh while on holidays with MDI in Madrid as part of a Spanish Exchange. (see page 7 for a full report).*

## Research Update

### Duchenne Muscular Dystrophy

*In my second research update, I am focussing on the research that is taking place into Duchenne muscular dystrophy. There is a vast amount of research taking place all over the world, mainly in the area of gene transfer, so I have only covered a small amount here. Anyone interested in this area can contact me for further information.*

Duchenne muscular dystrophy (DMD) arises when a mutation occurs in the dystrophin gene (dystrophin is a protein that makes up muscles and it is needed for muscles to work properly) located on the x chromosome. The x chromosome has genetic information from the mother - this means that when a person has DMD, it has been inherited from the mother (except in some cases where there is a spontaneous mutation of the gene).

As you may recall from the May edition of the newsletter, stem cell research has been taking place to try to find a way to fix the mutation in the dystrophin gene and find a therapy for DMD. In this article, I am going to give an update of the other research that is taking place into DMD.

There are various forms of gene therapy. One method would be to skip over errors in the gene, like using a type of molecular "patch". This would be like sticking a plaster over the parts of the gene that don't work, so the fault would be overlooked and at least some dystrophin would be produced. This would not cure DMD, but it would significantly lessen the symptoms. This technique has been attempted in mice but more research is needed to see if the technology could be applied directly in the human body.

Another type of gene therapy which is being tested in mice is one using insulin-like growth factor 1 (IGF-1). Usually, when muscles are damaged, IGF-1 and other proteins activate satellite cells in the muscle to repair the damage. In elderly people and to a greater extent in people with muscular dystrophy, the ability of muscle to activate these repairing satellite cells is decreased. The idea for the therapy is to transfer the gene for IGF-1 into a person with DMD. In America, this was tried in mice with DMD, and it was found that the muscle wasting associated with the condition was counteracted. One of the lead researchers, H. Lee Sweeney from the University of Pennsylvania, said "The muscles

stay in the state where kids (with DMD) are early in life". This therapy could be combined with stem cell therapy in the future. Another positive aspect of this type of therapy is that it doesn't depend on correcting the dystrophin gene, so it could be used to treat other types of muscular dystrophy which aren't caused by a defect in dystrophin.

Groups in France and the USA are looking into the possibility of using chemicals that stimulate the release of utrophin, a muscle protein that is similar to dystrophin. The group in France found that giving the chemical L-arginine to mice with DMD led to less degeneration of the limb and breathing muscles than in untreated mice. However, the technique would have to be developed to get a greater increase in utrophin to protect muscles completely against DMD, and further research needs to be completed to make sure that the treatment would be safe.

Another idea is to block the action of myostatin. This is a protein that inhibits muscle growth. Researchers in the USA have seen that mice with DMD that had the treatment had less muscle degeneration and were larger and stronger than untreated mice. This will now be tested in other animals.

In Ireland, Dr. Kay Ohlendieck, a name which might be recognised by some members, is researching the role of calcium into DMD. His team has noticed that dystrophin causes calcium ions to leak, so that the concentration of calcium in muscle cells is abnormal, and this plays a central role in the degeneration of the muscles. The eventual idea would be to have a therapy that would combat this, and therefore prohibit further muscle weakening. Again, this would not cure DMD, but it would be a great improvement.

As with all research into muscular dystrophy, it will take time for the research to progress enough for a treatment to be offered to people with DMD.

**Karen Jameison**  
Information Officer

*There is a vast amount of research taking place into DMD, and this article has just mentioned a small portion. If anyone would like more information, please contact Karen at the MDI office in Dublin, tel: 01 8721501 or email [info@mdi.ie](mailto:info@mdi.ie)*





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## **Muscular Dystrophy Ireland Conference Report Tullamore Court Hotel, Co. Offaly Saturday 14<sup>th</sup> September 2002**

MDI were lucky to have four speakers presenting at the annual conference, all of whom are experts in their respective fields. The talks went down very well, and were both informative and interesting. They certainly provoked a lot of audience participation, with a range of questions coming from the floor.

### **Dr. Richard Costello, Respiratory Physician, Beaumont Hospital, Dublin 9:**

Dr. Costello's talk concerned lung function in people with muscular dystrophy, and the measures that can be taken to make breathing easier. He explained that if the muscles are not strong enough, you do not get adequate oxygen intake. This leads to tiredness and lack of concentration. It is important that a person with muscular dystrophy sees their doctor on a regular basis so that their breathing can be monitored, and intervention can be planned if necessary. There are different respiratory aids available, which do the same job. In most cases, a mask is worn over the nose during sleep, which improves breathing and increases the amount of oxygen getting into the lungs. This is important because it means that breathing is improved and the quality of sleep is better. This, and the increased oxygen getting into the bloodstream, also means that awareness, concentration and activity is increased during the day, all of which lead to a better quality of life for the person with the condition.

### **Dr. Kay Ohlendieck, Dept. of Pharmacology, University College Dublin:**

Dr. Ohlendieck is due to move to NUI Maynooth in October where he will be Professor and Head of the Department of Biology. There, he will begin a three year research project entitled "Identification of novel therapeutic targets in dystrophic muscle fibres", which is funded by MDI. His talk concerned this research and previous related work.

Dr. Ohlendieck explained that when the brain sends the signal for a muscle to move, there is an influx of calcium in the muscle cells. In people with muscular dystrophy however, there is abnormal calcium binding, and this leads to muscle degeneration and weakness. The idea is that if you take a step back in the process and find a way to correct the abnormal calcium binding, you could prevent or slow down the muscle weakness. Dr. Ohlendieck's team will be using some of the most advanced equipment in the world, and a

very new technique called proteomics. This means the screening of proteins in a cell, organism or biological fluid. The aim is for this screening to lead to a new therapy for Duchenne muscular dystrophy.

### **Dr. Dominic Wells, Reader in Transgenic Biology, Imperial College School of Medicine, London:**

Dr. Wells and his team are involved in genetic research, particularly concerning Duchenne muscular dystrophy, but they hope that the techniques used can be applied to other types of MD. Dr. Wells explained that there are different types of genetic mutations or deletions, which lead to the different types of muscular dystrophy. The idea for treatment is to transfer a copy of the corrected gene into a person with MD, using a virus. Original gene transfer studies were carried out on very young mice that didn't have fully formed immune systems and where the muscle weakness had not progressed very far. However, there has been some exciting new research in older mice, which suggests that this type of therapy can correct current weakness rather than just preventing it progressing. There are some limitations with the research so far, in that you can't just inject the corrected gene into the muscles because viral vector injections do not spread very far. For example, if you wanted to treat a bicep you might need up to 60 injections to have any effect. Mice are very useful to use for the early stages of research, but the way muscular dystrophy presents in them is different to humans. However, there is more research taking place, and an approach where the corrected gene is injected into the arterial blood supply of monkeys has had positive effects.

Dr. Wells emphasised that gene therapy research is still at quite an early stage of development and that it will take some years before there can be human clinical trials. Until then, possibly the most beneficial treatment for people with the condition is non-invasive ventilation. However, results at the minute are exciting.

### **Mr. Derek Farrell, Secretary General, Disabled Drivers' Association of Ireland:**

Mr. Farrell spoke about the many benefits that membership of the DDAI can bring. The association provides an extensive information, advice and support service to members. Information available includes how to obtain appropriate driving and parking documentation, purchasing and adapting vehicles, claiming VAT, VRT, petrol refunds and road tax exemption. There is also a Driving Assessment Centre, where a person with a physical disability can learn to drive in a suitably adapted car.



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DDAI members can avail of other benefits, such as discounts on the purchase of new cars, ferry passages and package holidays. There is also a holiday bungalow in Wexford and a house in Ballindine, Mayo, which are available to members and their families to rent at a nominal rate.

Mr. Farrell also talked about a subsidiary of DDAI, Ability Enterprises. This provides a range of training programmes in the areas of computer and office skills, which give recognised qualifications. There is a centre-based computer course at Ballindine in Mayo but there is also a distance-learning programme.

DDAI and Ability Enterprises both operate in a way that emphasises ability, not disability, to support people to lead more independent lives.

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*If anyone would like more information on any of the above topics, please contact Karen at 01-8721501 or email [karen@mdi.ie](mailto:karen@mdi.ie).*

*Dr. Dominic Wells is also happy for members to contact him directly if they have questions on gene transfer research (email [d.wells@ic.ac.uk](mailto:d.wells@ic.ac.uk)).*

*Mr. Derek Farrell has given MDI a range of literature on the DDAI, including membership application forms, and these are available from Karen at the above number.*

## **MDI AGM 2002 Chairperson's Report**

*The Annual General Meeting of Muscular Dystrophy Ireland took place on Saturday 14<sup>th</sup> September 2002 in Tullamore. The following is a copy of the Chairperson Mr. Jimmy Murray's report:*

The past year has been an extremely busy one for all involved with MDI, both personnel and members. The main objective I had after taking up the position of chairperson after last years AGM was to set about increasing awareness of our organisation and the condition of Muscular Dystrophy in the wider community and enhancing the services that MDI provides nationwide.



*Jimmy Murray*

In relation to our awareness campaign the starting point was our National Awareness Day, which took place on St. Valentine's day. To complement this MDI printed new information leaflets and information packs. MDI has also updated its website to make it more informative to the general public. The two monthly newsletter is continuing to make a major impact among members and the

wider community. There are over eight hundred copies circulated nationwide between post and email and growing all the time. In relation to the enhancement of services the following are some of the areas we have concentrated on:

### Support Services

MDI has remained focused on ensuring that all our members and their families receive regular support and assistance. To improve on these services we have employed two youth workers, one covering the eastern region and one in the southern area. MDI are presently in the process of restructuring our Family Support Service in order to ensure members will be visited more regularly if required. There are a number of our FSW's who have a huge area to cover so the plan is to confine their service to a specific health board area so that there will be no over lapping. This will also result in less travelling for our FSWs and enable this service to focus in a smaller area and more time to deliver a more frequent and responsive service.

### Activities

There are three youth clubs set up at present, these are in the Cork, Kerry and the Dublin area. Over the coming year it is planned to expand on these clubs. Some of the activities that took place included a group of six members travelling to Manchester on 26<sup>th</sup> February to watch Manchester United play in their European Cup challenge match with Nantes of France. Clarenbridge Centre in Galway hosted two of our camps this year from the 13<sup>th</sup> to the 17<sup>th</sup> of May for adults and from the 27<sup>th</sup> of July to the 3<sup>rd</sup> of August for teenagers. The Younger Teenagers camp was held in the IWA Centre in Cuisle, Co. Roscommon from 1<sup>st</sup> to the 7<sup>th</sup> of July. The exchange trip with Madrid took place from 30<sup>th</sup> of August to the 8<sup>th</sup> of September. There were ten young adult members and ten PA's attending this camp. It is planned that the return visit will take place in the summer of 2003. MDI received a number of tickets for various concerts throughout the year from MCD and we would like to express our thanks to them.

### Personnel

There has been much additional staff taken on throughout the year. Mrs. Hazel Bridcut has taken up the position of bookkeeper with MDI. Hazel has been voluntary, doing the books for the past number of years. Ms Karen Jameison has taken up the position of Information/Administration Officer from the 26<sup>th</sup> of November. Ms. Mary Rose Howell has been appointed Youth Worker for the Southern Region and Ms Noeleen Fagan has taken up the position of Youth Worker in the



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Eastern Region. Ms Trudy Renshaw has taken up the position of FSW for the Southern and Mid Western Area for a period of six months, as Ms Mary O Sullivan had to take leave of absence due to family circumstances. Mr Willie Egan will be taking up the position of FSW for the Southeast region while Ms Marie Kealy takes maternity leave. We wish her well. Mr Noel Kavanagh has joined us for a 6 months trial period as a driver.

## Finance

DFI have been meeting with the Department of Health and Children on behalf of the six smaller voluntary organisations in relation to the late Tony Harmon review which had taken place three years ago and which MDI were a part of. MDI were invited to a meeting with the Minister Mr. Michael Martin from the Department of Health and Children on Thursday the 7<sup>th</sup> of March to discuss this review. The outcome from this meeting was that MDI received an increase in core funding. This is core funding for staff wages and associated costs. In relation to funding from health boards there are still a number that we receive no funding from but I would like to thank a number of Health Boards who are funding us for the first time and the others for their increased funding over the past year. MDI wishes to expand but without funding that is impossible. MDI installed a new accounting package 'Tas' and Payroll Package throughout the year. This has made it more efficient to control the administration of office accounts.

## Fundraising

The branches have been busy fundraising throughout the year from events such as concerts, sponsored cycles and head shaves, football matches, dances, church gate collections, etc. The main national fundraising events were the selling of the chocolates on our Awareness Day and our Christmas Cards. Folks, it is that time of year again so if anybody wants cards please contact the Dublin office.

## Research

Part of our mission statement is to fund research and I am delighted that we are once again supporting a project in Ireland. As you heard earlier today from Professor Ohlendieck's presentation, his project is a continuation of research into the role of calcium in Duchenne MD. This funding is over a three-year period and we wish him and his team in Maynooth College every success and we look forward to their findings in the future.

The year ahead MDI has a number of plans to ensure the continued development of the

organisation during the end of 2002 and throughout 2003.

## Increase the profile of MDI

The main event that MDI will be working towards is the national Awareness Day 2003. Foundations were set in 2002 for awareness raising and fundraising, and these will be built upon next year. Expectations are that the Awareness Day 2003 will be even bigger and better than 2002.

## Adult neurological clinic

The clinic in Beaumont Hospital will run for a pilot period of six months, and it is planned to continue the development of services in neurology, respiratory medicine, physiotherapy etc. for adults with neuromuscular conditions.

## Development of child clinic

The clinic for children which is presently being run in the CRC is working well, and MDI plan to continue to develop the services available for our younger members.

## Increase of services to members

MDI endeavour to provide a full range of essential services to members of the organisation and in 2003 these will be developed. It is planned to increase the availability of family support, respite, youth activities and camps, information services etc. to all members.

## Search for new office space

MDI has expanded over the year 2001-2002 and as the number of staff based in the MDI office in Dublin has increased, the need for more spacious offices has become a priority.

## Evaluation of services

MDI plan to evaluate the services that we provide to members to ensure that they are of the highest quality and fulfil the expectations and needs of all members throughout the country.

## Increase in core funding

MDI plan to continue lobbying for an increase in core funding to enable us to continue to provide a full range of services and to develop the organisation further for the improvement in quality of life for our members.

As I said at the outset in relation to our National Awareness Day a lot of time and effort, went into ensuring the success of the venture and I would like to express my sincere thanks to all the branches and the organising committee for the time given in the three month lead up to the 14<sup>th</sup> February. I would like to send a special word of



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thanks to the cast of Fair City and especially David Mitchell 'Jimmy' and Denise McCormack 'Farrah'. Thank you indeed also to everybody who lent their support on the actual day itself. I was very happy with the media exposure we received on the day and the gala concert which was held in the Royal Dublin Hotel. I would like to thank all the branches around the country, Dublin, Cork, Donegal, Mountbellew in Galway, Dundalk and last but not least our youngest branch, the Midlands for all their hard work throughout the year. Thanks also to all members of the National Council and I am grateful to them for their attendance at meetings during the year and for their contributions towards the decisions, which were taken at those meetings. I'd like also to thank my colleagues on the Executive Committee for their support and on their behalf and the National Council and all the members of MDI, I extend our thanks and appreciation to our Director, Joe Mooney and all personnel for their commitment, dedication and hard work during the year. 2001 to 2002 was a big and busy year for MDI but with all your support 2002-2003 will be even bigger and better.

Thank you.

*Jimmy Murray  
Chairperson - MDI*

## MDI Camps / Holidays Summer 2002

### Teenagers Camp 27<sup>th</sup> July - 3<sup>rd</sup> August Galway

On Saturday 27<sup>th</sup> July, a group of teenagers from Dublin, Roscommon, Mayo, Galway and Kildare headed to Kilcuan, Clarenbridge, Co. Galway. An activity packed week lay ahead.



*Des Mooney from Dublin and Bobby Keating sharing a birthday drink for Des's 18<sup>th</sup> birthday at the teenagers camp in Galway*

We visited many places including the Galway Races where a few bets were put down, but there were only two winners on the day - the totes and the horses.

We also went on the Connemara Cruise. It was a fantastic day, the weather was fabulous and everyone enjoyed themselves except for Wesley who felt a little sea sick. He did get over it quickly though.

On Wednesday we set off for Salthill to the Aquarium. Mary-Rose (Youth Worker, Cork) got to hold the biggest starfish. We got the chance to feed some of the fish and a few of us got to touch a baby shark.



*Paul Breen,  
from Dublin  
at an  
"Austin  
Powers"  
theme night  
disco, at the  
teenagers  
camp in  
Galway*

Thursday evening was the finale of the week, when we celebrated Desmond Mooney's 18<sup>th</sup> Birthday with an Austin Powers Theme Disco and Karaoke. Des got 18 kisses and a pint of Guinness (made from coke and ice cream). During the evenings events we had a visitor of a Galway Bat who wanted to join the party!

Friday included a trip to the cinema to see Men In Black II and some shopping. Then a pick-up from Dominoes Pizza on the way home concluded the Teenagers Camp.

I hope all who went had a great time and I look forward to seeing you all again.

*Noeleen Fagan  
Youth Worker-MDI*

## FOROIGE YOUTH LEADERS

**MDI are looking for a group of youths between the age of 14-17 to attend leader training in Dublin in early November. If you feel that you would be interested in attending this training course and becoming a leader with Foroige, contact Noeleen (Youth Worker) at the MDI office.**



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## Spanish Exchange 30<sup>th</sup> August - 8<sup>th</sup> September

Just over two weeks ago, a group of twenty people returned into Dublin Airport extremely tired but refreshed after ten days in the hot sun of Madrid. Eleven MDI members, four staff and five personal assistants had spent an amazing ten days in the fabulous and fantastic city of Madrid.

Throughout the ten days the group visited the Prado Museum famous for its hundreds of amazing paintings. There was a fantastic exhibition on the day we visited. The El Prado Museum boasting these brilliant exhibitions lacked the same high standard of accessibility.



"The Three Amigo's" Daragh Tyrell, Colin Boland and Andrew Nolan enjoying the sights and sunshine in Madrid.

We visited the amazing aqueduct in the town of Segovia and walked through the small narrow cobble stone streets looking in the shops picking up a few little presents and souvenirs from family and friends at home.

A visit to the Cultural City of Madrid allowed us three hours of shopping. The girls had a great time shopping but not so much can be said for our male members, Sean and cousin Ronan. This was an ideal time to buy our invisible friends their presents!

A stop off by some of the group on the way back to our accommodation was gladly met by the football enthusiasts of the group. A quick trip into the Real Madrid Stadium was to some the highlight of the trip whereas to others it was a real insight into the inaccessibility of Madrid. There was no way to get into the stadium for many of the group. It was up to Mary-Rose and myself to do the

running in and shopping for those who couldn't get in themselves.



Pictured in Aranjuez, Spain on a hot sunny day are Janette Kiely (Cork) and Sammy Brill (Westmeath) while on holidays on an MDI Spanish Exchange.

During the days there was always plenty to do. There was horse riding with our resident Indian Bobby. There was bracelet making, baking doughnuts, potters wheel and of course making our own traditional Spanish paella and sangria. As Sinead, Seamus and Paul would say "Mucho, Mucho, Sangria." Every evening the group got together and listened to traditional Spanish or Irish music. The Irish group learned the words to the Macarena, joined in dancing to it and also learnt the moves to the new song that is to be a big hit in Ireland soon 'The Ketchup Song'!!

The trip was a huge success and a fantastic time was had by all. We will not forget the freezing cold pool and Colin trying to get into it. Nor will we forget Janette and her rendition of the wheels on the bus go round and round. And to sum it all up as Daragh would say "we did it for the craic".....

**Colin Boland (MDI Member) & Noeleen Fagan (Youth Worker)**

## Muchas Gracias - Thank You

**A very big thank you to all our new friends in Madrid - you really made us feel welcome. We are looking forward to meeting you again in the summer of 2003.**

**Thank you also to Leargas who provided the support and funding which made this exchange possible.**



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## Switzerland, August 2002

*Last August, MDI member Marian Gilligan from Dublin returned from Switzerland after a very enjoyable and hassle free holiday. Marian, who uses a wheelchair, wrote the following article upon her return and asked us to include it in our next newsletter, because of the wheelchair accessible facilities etc. Marian writes .....*

Described as a "gem of a holiday", the brochure presented a very appealing image of a perfect holiday – fresh mountain air, stunning scenery, accessible venues (even by cable car and railway) and as I read on I wondered if this holiday was too good to be true. Being a wheelchair user myself, I was quite well aware of the problems that could arise from inaccessible transportation to inaccessible venues, where one's dream could turn to the worst of nightmares. No one I knew had ever heard of Chalfont Line Holidays. I had only ever communicated with the tour company by telephone, so it was either take a chance and try my luck, or stay at home.

I had first heard of the travel company about six years ago while browsing through a magazine rack in the Disability Resource Centre in North Great George's Street, Dublin. I was very impressed by their brochure which offered escorted help to disabled people wishing to travel with a group on holidays. Real holidays these were, to exotic locations like Florida, South Africa, Malta, Switzerland and places closer to home like Jersey, Devon, Cornwall and Ireland. The group was based in London and provided winter flying holidays or coach hours. The prices were very expensive but when one considered the level of care provided, it was clear to see where the money was going. A friend of mine came to accompany me on my holiday. With great excitement we set off.

We decided to bypass London and meet the tour group in Zurich which consisted of twenty nine people - fifteen disabled people, 5 friends or spouses, the Tour Company owner and Tour Group Leader and seven care staff. We spent the week on the shores of Lake Lucerne. During the course of the week, we did manage to travel up 7,000 foot in a cable car, drive for 45 minutes up a mountain in a little train and take numerous trips by boat to towns on different parts of the lake. The lake shore was very accessible and wheelchair friendly and had the festive atmosphere of foreign parts. While all the rooms in the hotel were not completely accessible to wheelchair users, the leaders provided alternative arrangements and helped out with difficulties. In fact a notable feature of the week was the

cheerfulness with which tasks were performed - nothing seemed too onerous.

Dinner was served at 7.30pm every evening after which one could join with others for a drink for as long or as short as one wanted to stay! Exchanging experiences and sharing stories was as much part of the holiday as anything else.

So it was really as the brochure had promised – a gem of a holiday and I was very glad I hadn't missed it. **Enquiries to Chalfont Line Holidays, Chalfont House, 4 Providence road, West Drayton, Middlesex, UB7 8HJ, London. Tel: 0044 1895 459540.**

## Summer Youth Group Activities Dublin

Members of the Youth Group had a fun packed two weeks from 6<sup>th</sup> -21<sup>st</sup> August.

Activities included:

- **Dublin Zoo**, Where we got to see the Baby Sealion Alex, only two months old. We also got to pet the goats and see all the piglets running around. We had a look in the Bat House and the Reptile House. It was a good day out and we hope to visit again!
- **Cinema**, Here we went to the cinema to see "Eight Legged Freaks" and played bowling (with the lucky black ball).
- **Arts & Crafts**, We created our own personalised plant pots and planted flowers in them.
- **Army Barracks**, We also got an invite from the Army Barracks in the Curragh to visit them and have a look around.

If you are interested in attending the youth club in the future phone Noleen Fagan for an application form on (086-6066109) or (01-8721501)

## News from the South

### Cork Flag Day

Cork Flag Day was held on Thursday 11<sup>th</sup> July in various shopping centres throughout Cork city. I would like to thank the many volunteers who gave up their free time, because without you the day would not have been possible. We are very grateful, thank you.

### Limerick Flag Day

This was the first time Limerick held a flag day for MDI. It was a very successful day and thanks to everyone who made it possible.

## Fundraising

On Thursday 8<sup>th</sup> August, a fundraising event took place in the Blackrock Inn, Cork City. Many members came to show their support to Frank Hurley, who kindly offered to shed all hair and raise funds for MDI. A great night was had by all, even by the Lord Mayor, who got a chance to snip some hair himself!!! The total amount raised is not clear yet, as the money is still rolling in!! If anyone has outstanding sponsorship cards, please send them back to Frank as soon as possible. Thanks to everyone who donated money to this event and above all, thanks to Diedre Walsh, Frank Hurley and everyone who put in a lot of time and effort to make the night a success.



Frank Hurley, before shaving his head



Frank Hurley after shaving his head

## Kerry News

On Friday 9<sup>th</sup> August a group of young people from Co. Kerry went to Fenit Sea World, to take a look at life beneath the Atlantic waves. We got the chance to see many different sea creatures. Afterwards we went to McDonalds for some lunch and ice-cream!!!! A great day was had by all, and we're looking forward to the next outing.

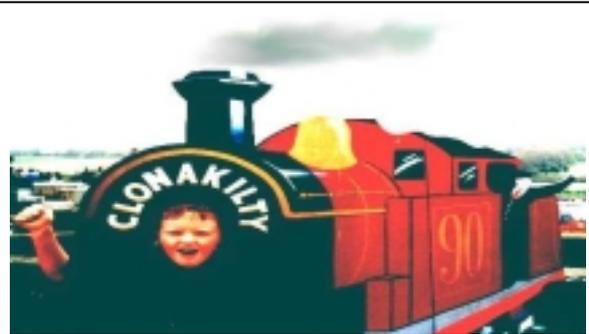


David Tobin from Tralee pictured at Fenit Sea World during Cork summer camp.

## Cork Camp, 12<sup>th</sup> - 16<sup>th</sup> August - by Rachel Clark (age 10).

We had a great day on the Monday at the Model railway village in Clonakilty. We had a quiz and everyone got a prize!!! We went to the park for a picnic and played games and got ice-cream from the ice-cream man! On Tuesday we went to Caleb's house where we watched a video - it was very good. We had pizza and chips for lunch and then went out to play soccer. On Wednesday we

went to the army barracks. This was excellent - we looked at all the guns and went to the museum. On Thursday we went to McDonalds for lunch and then we went to the cinema to see "Spy Kids 2." It was very good. On Friday we had a huge party. We got to see a real fire breather named Brian - it was a bit scary. Then Connor the Clown came - he was very funny. He played lots of games and painted our faces - I was the pink power ranger. It was a great summer camp!!



Joseph Lane from Cork @ Model Railway Village, Clonakilty. Co. Cork during Cork summer camp.

## Cork Branch AGM

The Cork Branch held their AGM on 11<sup>th</sup> September in the Blarney Park Hotel. After many dedicated years of hard work, Eileen Wilkins and Margaret Buttler stepped down as Treasurer and Chairperson respectively. The Cork Branch would like to thank them most sincerely for all their help down through the years.

Eddie Fitzgerald has taken on the challenge of Chairperson. Eddie has been an active member of the Cork Branch for many years. He is dynamic and has many great ideas and the Cork Branch is delighted to have him on board.

June Scannell, who has also been involved with MDI throughout the years has taken on the role of Treasurer of the Cork Branch. As June has many years experience of serving on the committee, she will be well able to look after the financial matters.

Jean Lane has been Secretary of the branch for the last year, and we are delighted she is staying on board. Jean is very efficient in her work and is very dedicated in helping any member of the Cork Branch in any way she can.

The next branch meeting will be held on Wednesday 9<sup>th</sup> October. Venue to be confirmed. Phone the Cork office (021 4309047) for details.

## Cork and Kerry Youth Clubs

On behalf of all the participants of the Cork and Kerry Youth Clubs, I would like to thank David O'Mahony and Niamh Magnier for all their help throughout the year in making our clubs a success.

Mary-Rose Howell



# MDI News Update



Two monthly newsletter - Issue seven, September 2002

## MDI Respite Service

*In recent weeks, many people have inquired about the Respite Service which is available to MDI members. The following article has been included once again to clarify the services members can avail of in relation to respite:*

MDI's respite service provides practical assistance to families and members in need of such support. This is done in various ways, depending on the needs of the member concerned. Help can be provided in the home for a weekend, a few hours during the day, or a night turning service. We will also try to provide assistance in an emergency situation where for example a parent of a child who has muscular dystrophy becomes ill.



*Siobhan Windle  
Respite Co-ordinator*

MDI also provides financial assistance towards family and individual members holidays where one of the members has MD and can not take part in the youth camps or adult holidays organised by MDI during the summer. If parents or guardians take a holiday and neither have MD, MDI can not provide financial assistance towards their holiday, however MDI can pay toward the cost of a careworker or personal assistant to replace them while they are away.

At present MDI does not employ any full time careworkers or personal assistants. However we can help you to find the appropriate careworker or personal assistant.

The aim of the respite service is to be as flexible as possible and to work with what the member requires. We will also try to link in with the respite service providers in your local area.

If MDI employs a careworker or personal assistant chosen by the member or family the person will have to register at their local tax office and get their "tax credit certificate with standard rate cut off point" The tax office usually sends out these forms to MDI very quickly. They person may already have a PPS number which they can give instead.

MDI provides short term respite. However we will continue to provide respite where there is no immediate alternative. We will help you link in with the care attendant and personal assistants schemes run by the various branches of the Irish Wheelchair Association, the Centre for Independent Living, Rehabcare, and the Health Boards around the country.

If you think you may need a break or an on going respite service you should contact the MDI Family Support Worker in your area giving them as much notice as possible. If your are unable to contact them in the case of an emergency you can contact the respite Co-ordinator in the MDI office in Dublin.

MDI also runs youth camps for children of 11years and older, teenagers and a short holiday for adult members. If you are interested in any of these activities please contact your family support worker in your area. Unfortunately the places on the holidays are restricted. If you do not get an opportunity this year we will try to facilitate you the following year.

This respite service relies on funding from various sources. Some Health Boards are aware of the need for funding for this vital service and are increasing their grants. However other Health Boards supply a very small amount of funding. There are still areas of the country which are not funded. MDI has to raise funds through various fund raising events to supplement this under funding so that all the members of MDI will be able to benefit from the respite services.

**Siobhan Windle  
Respite Co-ordinator MDI**

### New MDI Driver

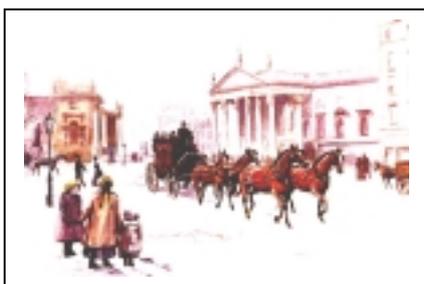
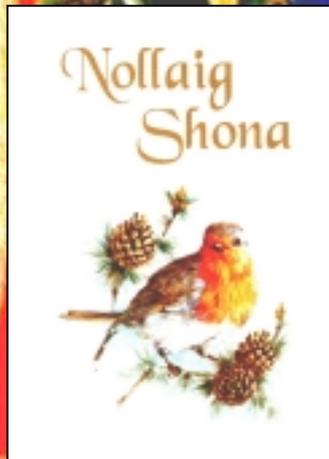
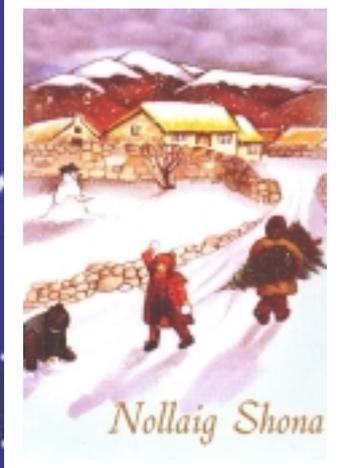
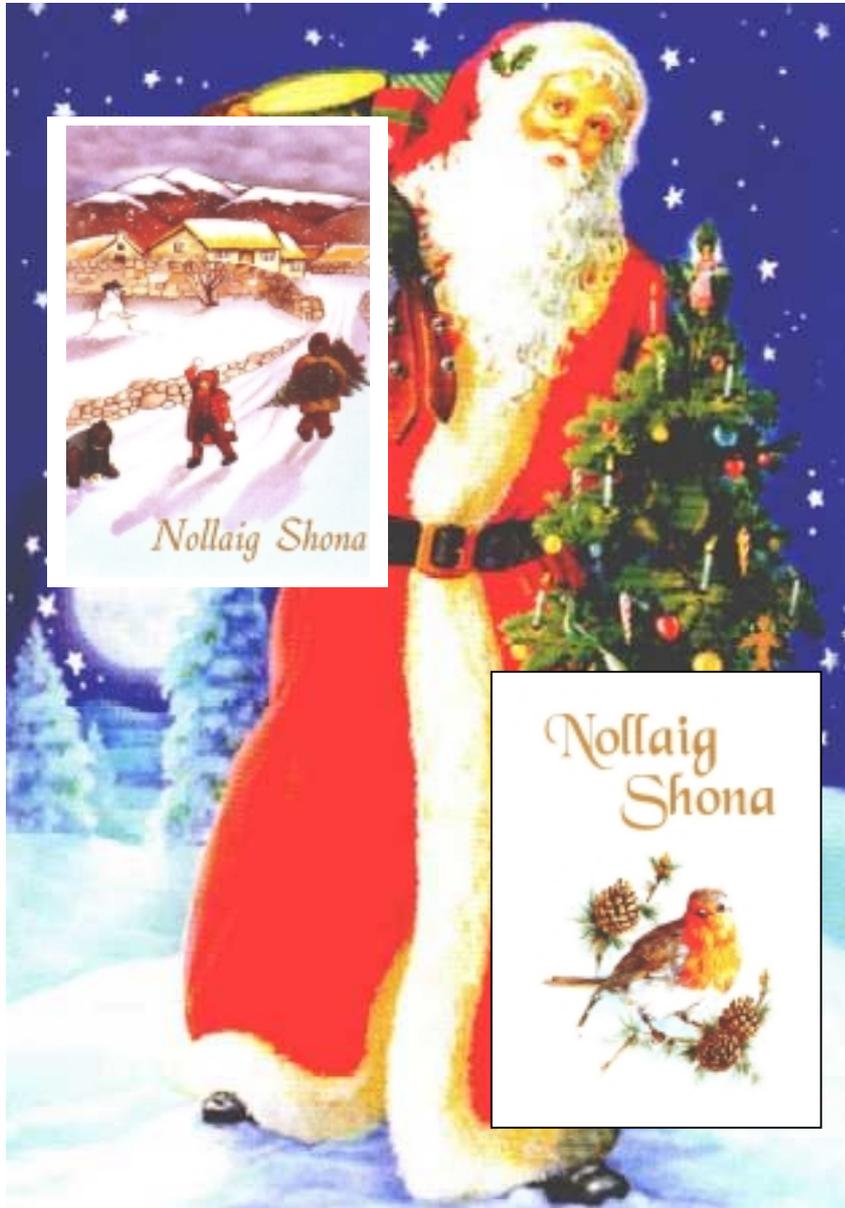
MDI has recently employed a driver, Mr Noel Kavanagh, who will be working with us for a 6 months trial period.

If you require transport from train stations etc. to any MDI events, hospital appointments or clinics in Dublin phone the MDI office.

## MDI Christmas Cards 2002

This page features a selection of Christmas cards available from the MDI office this year. The cards featured below are sold in packs of 8 (one of each card, with envelopes. Size A5) for €5.00 a pack (plus 50c postage per pack). Verse inside card reads: "With the Seasons Greetings and All Good Wishes for the New Year"

Actual card size



There are also plenty of last years small cards available. These cards are also sold in packs of 8 (one of each card) €4.00 a pack (plus 50c postage per pack). To order any of these cards, contact the MDI Office.



## Medical and General Mobile Specialists

**parfit** offer a comprehensive range of specially adapted vehicles to meet with each individual client's requirements.

**parfit** takes pride in providing an unsurpassed level of Quality, Service, Reliability and attention to detail. Our highly skilled, motivated and talented craftsman are dedicated to providing you with a product second to none. Each of our customer needs are personally handled by our directors, discussed in detail, evaluated and executed with confidence.

**parfit** use only the finest quality materials and components to guarantee reliability with a long and productive life for all of our products. A privately run firm we have grown from a small business, to be leaders, in the market place, indeed examples of our work can be found from Dublin to Dubai.

**parfit** philosophy; to continue improvements that will benefit each and every client.

### Custom-made

**parfit** built minibuses / vans can be custom made to your needs and fitted with:

- Access ramps and lifts for wheelchairs.
- Wheelchair restraints.
- Passenger restraints.
- Restraints for passengers with special needs.



**parfit** looks forward to your business and solving your Transportation needs.

**For further information contact Pat Fitzsimons at:  
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