MDI News Update

Issue 33 • Two Monthly Newsletter • May/June 2007

Hi Everyone,

Welcome to the latest issue of the MDI News Update! In this issue, Karen Pickering, our Information Officer has certainly been busy writing, as this edition has lots of information on research into muscular dystrophy and management of the condition (see pages 2 to 7).

With news from the Youth / Respite Workers on pages 8 and 9, transport issues on page 10 and fundraising articles etc thereafter, there should be something to interest everyone. Happy reading and until next time, take care.

Hubert McCormack, Editor

MDI Members & Staff pictured on camp in Fermanagh in April 2007.

See a full report and more photographs on pages 8 and 9.

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Research Update

PTC124 as a Potential Therapy for Duchenne Muscular Dystrophy

Promising results were published on 23rd April in the journal "Nature", and subsequently repeated in the media, about the safety and efficacy of a drug which could potentially be used as a treatment for 10-15% of boys with Duchenne MD. The following article was published by the Research Department of the Muscular Dystrophy Campaign, UK, and is used with their kind permission.

An overview of the PTC124 research

The Nature article reports that the drug, called PTC124, was found to significantly restore the production of full-length dystrophin and muscle strength in a living organism. The article describes the results of experiments in which PTC124 was tested in human cell culture and an animal model for Duchenne muscular dystrophy.

A genetic condition can arise due to a mutation in a gene which carries the information needed for cells to produce a fully functioning protein.

In the case of Duchenne muscular dystrophy the condition is caused by a number of different mutations in the dystrophin gene, one of which is called a "nonsense mutation".

Nonsense mutations do not only occur in Duchenne muscular dystrophy, but are also found in other genetic conditions, like cystic fibrosis. These nonsense mutations prevent the cell's production machinery from accessing all the required information stored in a gene. This results in the production of a shortened, non-functional protein – the production of the protein is stopped before it reaches its full length.

PTC124 binds to components in the cell's production machinery called ribosomes and "convinces" them to ignore the early 'stop' signal, so that a complete, functional protein is produced. The drug will not repair the genetic error and therefore will need to be taken throughout the life of a person affected by the condition.

The article published in 'Nature' describes the results of experiments where PTC124 was given to mice carrying a nonsense mutation in the dystrophin gene. The researchers found that full-length dystrophin production was partly restored which was associated with increased muscle strength. The article also states that the drug has no effect on the production of other proteins in the body, which was an important safety issue.

About 10% to 15% of boys with Duchenne muscular dystrophy carry a nonsense mutation which changes the information in the DNA into a stop signal. For these boys the drug could present a potential treatment, but for the majority of boys with Duchenne muscular dystrophy, whose condition is caused by different mutations, the drug would not be suitable.

PTC Therapeutics, the drug company behind the technology, has also published results of phase-I clinical trials in which the safety of the drug was tested on 62 healthy volunteers. They found that the drug was generally well tolerated and was safe enough to be taken to the next stage. Currently a phase-II clinical trial is in progress in the United States and 22 boys with nonsense mutations aged between 5-12 years old are participating in this study. The clinical trial was designed to last eight weeks during which two different doses of PTC124 were tested. Muscle biopsies were analysed before and after the drug was given to evaluate the effect on dystrophin production in addition to further chemical and functional tests.

The results of this phase-II trial have not yet been published, but are expected shortly. If the results of the phase-II clinical trial are positive, a phase-III clinical trial will be performed to evaluate the effects of the drugs in a larger number of patients. The results of the phase-III trial must also be positive before the drug could be licensed as a treatment.

Research Presentations

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

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

We will have a summary of both these presentations in the next issue of this newsletter.

Quotes from researchers and clinicians about this research

"The findings described in the Nature article by Professor H. Lee Sweeney and colleagues are encouraging, particularly in the light of the clinical studies which are being carried out in the United States. This drug appears to have the potential to become a treatment in the longer term for some people with Duchenne muscular dystrophy. The Muscular Dystrophy Campaign is looking forward to the publication of the full results of these clinical trials so that we can see more clearly what the prospects and possible timescales are for treatment."

Dr. Marita Pohlschmidt, Director of Research, Muscular Dystrophy Campaign

"This is an incredibly exciting new drug, which has the potential to add decades to patients' lives. In Scotland, we have already increased life expectancy of patients from late teens to late 20s. This drug is one of many new treatments which could help us improve that even further."

Dr Douglas Wilcox, Senior Lecturer & Honorary Consultant in Medical Genetics at Glasgow University

"It will be very important to see if this exciting new drug can be used safely and effectively in the clinic. But PTC124 or similar products could only ever be a small part of the solution as the vast majority of cystic fibrosis patients have a different type of mutation from the rare nonsense mutation which is specifically targeted by this class of compounds."

Professor David Porteous at Edinburgh University, a researcher specialising in cystic fibrosis

Questions & Answers

Q: When will a treatment be available?

A: This is a very difficult question to answer. The results of the preclinical and clinical studies published so far look encouraging and if PTC124 lives up to its promises then the drug could be licensed in the coming years. However, it is important to understand that a clinical trial is not a guarantee for a treatment, but rather a way to find out whether it works in a human being. It is therefore important to find out exactly what the effects of PTC124 are on the production of full length dystrophin and the restoration of muscle strength in boys with Duchenne muscular dystrophy before one can make any predictions about the prospects and timescales for a treatment.

Q: Will all boys with Duchenne muscular dystrophy benefit from this new drug?

A: PTC124 would only be suitable for about 10-15% of boys with Duchenne muscular dystrophy. In the majority of cases the drug will not be effective. Th]is is because it can only treat those boys who have a "nonsense" mutation which tells the cell's protein-producing machinery to stop prematurely.

Nonsense mutations can be found in other genetic diseases such as cystic fibrosis and in the case of Duchenne muscular dystrophy the machinery produces a shortened, non-functional dystrophin protein.

In order to find out if an affected boy would benefit from taking PTC124, a genetic test is required to identify the specific genetic mutation.

Q: How can I get involved in clinical trials?

A: Clinical trials for PTC124 are currently performed in the United States and the charity is not aware of any immediate plans for clinical trials in the UK. A clinical trial is a series of studies designed to test the safety and efficacy of a drug or a treatment. A phase-I study in healthy volunteers has already been completed for PTC124 and the results indicate that it is safe for human beings to take the drug. The efficacy of the drug has also been tested in boys with Duchenne muscular dystrophy who carry nonsense mutations, but the results have not yet been published. PTC Therapeutics (the company developing the drug) has indicated that the outcome of the phase-II study is promising, but it is important to understand the detailed results of this study before making any predictions about moving into the next phase. The next step, a phase-III study, will include more boys will be included, possibly also from countries outside the US. To participate in a clinical study like this, it is important to know the specific genetic mutation which is causing the condition. It is also important to let your clinician know that you are willing to take part in a clinical trial.

Further information & links

The magazine, 'Nature', (www.nature.com) is subscription only so the original article is not freely available. The article itself is written in medically technical language with no summary in layman's terms. You might like to take a look at news articles in The Times or BBC News.

You can find out more about the Muscular Dystrophy Campaign at www.muscular-dystrophy.org

MDEX Consortium Update Meeting

A meeting of the MDEX Consortium took please on Friday 9th March 2007. This research project is part funded by MDI and the following is a update of where it is at.

- The first clinical trial is almost ready to begin. Paperwork had to be completed for all referring centres and this had to be reviewed by the MHRA (Medicines and Healthcare products Regulatory Agency). This was approved in April 2007.
- Participants have been identified for this first trial. 9 were going to be recruited but if its looking good then they will probably only need 6 to participate. **There will be no therapeutic benefit to any of these participants.**
- The timeline should be:
  April - Recruitment
  1 month - Preparation
  May - Trial begins
  End of Summer - Completion
- If this first stage is successful, the systemic trial could be started by early 2008. Toxicology work will be carried out over summer 2007 in preparation for this trial.
- An ENMC (European Neuromuscular Centre) workshop took place to look at planning for what happens if this therapy works.
- There are differences between the UK and Ireland with regard to running clinical trials and gaining ethical approval. MDI is currently working to see if a system can be put in place whereby Irish boys could volunteer for future clinical trials in the UK. It is important to remember that this stage of the trial is non-therapeutic. Even the systemic trial will have to start with a safety trial, so the boys taking part at the minute will not have a therapeutic benefit.
- MDI funding has been used to:
  - Develop the dosing strategy and route of delivery of antisense oligonucleotides (AOs).
  - Identify AO sequences for skipping additional exons in order to broaden it out and potentially benefit more people.
  - Creating the best AO formulation.
  - Determine how to target cardiac muscle as well as skeletal muscle.

MDI Information Officer Karen Pickering (3rd from left) presents the MDEX Consortium in London with a cheque for £25,000 stg as our second contribution towards MD research.

Official Announcement of MRCG / HRB Joint Funding Scheme

On 2nd April 2007, Ms. Mary Harney, Minister for Health, officially announced the recipients of the Medical Research Charities Group / Health Research Board Joint Funding Scheme 2006, in the Royal Irish Academy, Dublin.

MDI received funding towards two pieces of research, Prof. Kay Ohlendieck's "Identification of Novel Biomarkers in Dystrophic Heart and Muscle Fibres Using Comparative Proteomics" and the MDEX Consortium in the UK's "Restoring Dystrophin Expression in Duchenne Muscular Dystrophy: A UK Consortium for Preclinical Optimisation and a Phase I/II Clinical Trial Using Antisense Oligonucleotides". Mr. Joe Mooney, Director, Mrs. Karen Pickering, Information Officer, and Prof. Kay Ohlendieck, grant recipient, attended the official announcement.

MDI would like to thank the MRCG and the HRB for the opportunity to participate in this scheme.

The Management of Muscular Dystrophy Information Day

Saturday 10th March 2007

This information day took place in the Red Cow Moran Hotel, Dublin and was well attended. For all those who couldn't make it, here is a report on the presentations on the day. The speakers were all excellent and we would like to thank them very much for their participation.

Pamela Foley

Physiotherapist
Central Remedial Clinic

When a child is referred to the muscle clinic at the CRC, they will have a full physio assessment, involving assessment of the range of movement, strength testing and level of function. This may take more than one session. A programme would then be developed for the child, involving:

- A consistent stretching programme (try to maintain range of movement. It is easier to maintain than regain movement).
- Encouraging activity.
- Breathing exercises.

Light exercise such as swimming or horseriding can be beneficial, but not resistance exercise (such as weight training). Team sports are not recommended so much as it becomes harder to participate as the condition progresses.

Night splints can be very effective but they need to be introduced early and there can be problems with compliance. Orthoses must be comfortable and checked as the child grows to ensure they still fit correctly. Orthoses worn during the daytime are not recommended for Duchenne muscular dystrophy, but can be useful for children with HMSN (Charcot-Marie-Tooth) and milder spinal muscular atrophy.

Generally, younger children and older children and teenagers will attend muscle clinics at different times. The orthopaedic surgeon attends the older clinic.

Steroids:

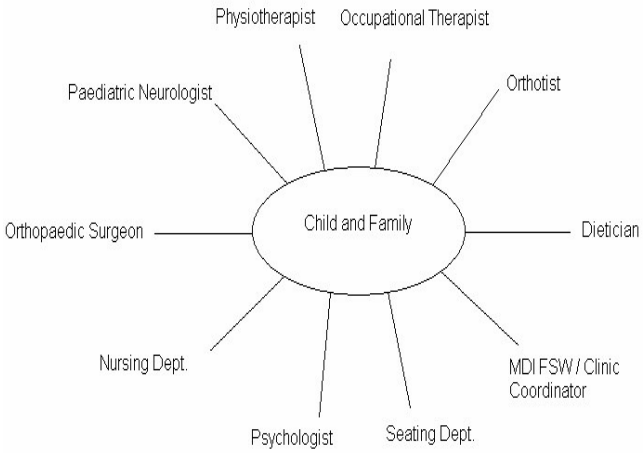
- Steroids are being introduced earlier now for boys with DMD, which can be around age 5, when boys are slower on timed tests.
- They are introduced following a lengthy discussion with parents.
- They may add up to 18 months on to the length of time a boy can stay on their feet.
- Side effects can be minimised, e.g. with dietetic input to minimise weight gain, calcium supplements to minimise risk of osteoporosis.

Home and School:

- The introduction of a hoist can help, and it gets easier to use with practice.
- A manual wheelchair can be initially introduced for family outings, shopping etc.
- It is becoming easier to access facilities in schools, but there are still problems getting Special Needs Assistants.

Management of the Spine:

- A baseline spinal x-ray is taken when a child starts using a chair full time, and this is followed up by 6 monthly x-rays to check for any scoliosis (curvature of the spine).
- Spinal surgery is being performed earlier, when the spine is at a milder stage of curvature.
- There is a less dramatic change in seating requirement when the surgery is performed earlier.



With the multidisciplinary team in the CRC, you can see a range of people:

Cardio-Respiratory Involvement:

- When the heart and breathing need to be monitored, children can be referred to Dr. Slattery in Temple Street for respiratory monitoring and to Dr. McMahon for the heart in Our Lady's Hospital, Crumlin.

Moving to Adult Services:

- As a teenager gets older, it is important now to link in with adult services so they will be familiar to them, and the transition from child to adult services will be easier.

Prof. Richard Costello

Consultant Respiratory Physician
Beaumont Hospital

The respiratory muscles become affected by muscular dystrophy. When someone is referred for respiratory monitoring, the procedure is:

- A history is taken – checking for morning headaches, excessive daytime sleepiness, ankle swelling, suddenly starting to wake during the night.
- Arterial blood gases are checked – Carbon dioxide (CO2) retention is a feature of later stages of MD.
- Pulmonary function checks can be performed, such as the SNIP test, a simple test to measure nasal pressure or spirometry, a test to assess airflow.

It may be necessary for a person to begin using artificial ventilation, such as the BiPAP. This can be used while asleep and helps people to get more air in and out of their lungs. It is a very effective device, although does take some time to get used to. Respiratory problems generally develop slowly, and it is a good idea to get devices checked to make sure they are still effective.

Recommendations:

- Try to avoid chest infections as much as possible, as they put extra demand on respiratory muscles.
- Deal with chest infections immediately to minimise effects. Have a back-up prescription in the house for a non-specific antibiotic. Also keep a cough bottle in the house, an expectorant, not a cough suppressant.
- It may be useful to use a device that can help you to cough.
- Go to the doctor to get checked out when you have a chest infection. Recurrent infections can also be a sign of something else, e.g. asthma or heart problems.

Dr. Afif El-Khuffash

Specialist Registrar in Paediatrics
Our Lady's Hospital, Crumlin

- Dystrophin, the protein that is found in skeletal muscle is also found in cardiac muscle. Boys with Duchenne MD produce either none or very little dystrophin. Its absence in the heart means that the heart muscle becomes weaker. Heart muscle can be affected, even when there are no outward symptoms.

- Dilated cardiomyopathy can result, where the heart becomes bigger and it can also develop an abnormal rhythm.

- If untreated, it can lead to:
  - shortness of breath
  - tired constantly
  - palpitations
  - poor lung function
  - poor appetite
  - worsening of general condition

- The idea is to intervene before these symptoms develop. Screening should start for boys with Duchenne MD by 10-12 years of age with follow ups every 6 months.

- A tissue doppler is a test to pick up heart deterioration. It can be done in a few minutes in outpatients. An MRI is also good, but it requires the child to lie still in the machine for half an hour so the other test is preferable.

- If tests show the heart to be affected, different treatments can begin, such as ACE inhibitors, angiotensin receptor blockers and digoxin.

- There is also a new drug now, carvedilol. This has been shown to not only delay the progression of heart problems, but also to potentially reverse effects and improve symptoms. They would like to start this treatment as early as possible. At the beginning, the child has to be monitored in hospital for 24 hours in case of any side effects, but it is generally very safe and the medication only needs to be taken twice a day.

Rachel Glennane
Occupational Therapy Manager
Central Remedial Clinic

Housing Adaptations: What to consider?

- Lift vs. ground floor – is there space on the ground and first floor for a lift? What sort of lift is needed (stairlift, platform lift, through floor lift). Need to check the size and weight requirements of the lift and whether the controls are accessible. If a ground floor extension is preferable to a lift, is there space in the current house and garden for one? Will this mean that the parents / carer will be sleeping upstairs and the child downstairs?
- Shower vs. bath – what space is available? Is there appropriate access into and support in the bath? Or would a level access shower be preferable? What sort of shower chair could be used? Take into account changing facilities, the needs of the family and preference of the person with MD.
- Hoists – available with both manual and electronic controls. A ceiling hoist on an overhead tracking system takes up no floor space.
- Environmental controls – can allow a person with a disability to open and close doors, windows, curtains, blinds; make and receive phone calls, turn on and off lights and other appliances, control TV, DVD, stereo and other leisure devices.
- The Neater Eater is a device allowing someone to feed themselves. It is available to try in the OT Dept. in the CRC.

General Tips

- Plan ahead
- Be your own project manager
- Keep a contact list (Community OT, Housing Officer etc.)
- Keep copies of all documents
- Find experienced people
- Make lists.

School and the EPSEN Act 2004

- The Act includes a commitment to providing an assessment of needs for every child with disabilities or other special educational needs, that covers their physical, cognitive and educational needs.
- The National Council for Special Education (NCSE) has responsibility for improving coordination between the education and health sectors in supporting children with special educational needs.
- The Special Educational Needs Organiser (SENO) convenes a team of people to prepare the Individual Education Plan (IEP) for the child. The team can include parents, the child (having regard to their age and special educational needs), OT, physiotherapist, psychologist, teacher, principal.
- The IEP can include the special educational needs of the child, the special education and related support services to be provided to the child and the goals which the child is to achieve over a period not exceeding 12 months.
- The SENO assesses applications for resource teaching and Special Needs Assistant hours. They make recommendations to the Dept. of Education for school transport and other resources such as assistive technology.

Useful Contacts

- www.assistireland.ie
- The Access Directory (copies available from Information Officer in MDI)
- CRC MD clinic
- CRC Assistive Technology Dept.
- Enable Ireland Assistive Technology
- National Council for Special Education Needs in Trim – www.ncse.ie
- Comhairle – www.comhairle.ie and local Citizens Information Centre.

Rachel Glennane, O.T Manager CRC, presenting at the MDI Conference in March

News from Youth & Respite Workers

Hi everyone, Ciara Kelly here (YRW Cork/Kerry) to give you an update on recent youth work activities around the country, and what a busy month it has been with this years Easter Camp taking place at the end of March. So where do I start….

On the 31st of March, MDI members set off from many different parts of the country to attend the first camp of this year in Share Village, Co Fermanagh. The journey proved to be a bit of a trek for some but I do believe that the Kerry bus in particular sang the journey away!! We reached the centre at around 8pm where we had our first meal of the week and the remainder of the evening was spent catching up with everyone and settling in.

The next day was really chilled out, after lunch the entire gang headed for Lisnaskea, our neighbouring village where a local parade was well underway. It proved to be a success among the MDI onlookers! Afterwards, we headed back to Share Village where we watched DVDs and of course played some playstation.

Monday was an activity filled day, with some people designing their own t-shirts and others opting to do archery. In the afternoon, we all split up into groups and set out to make our very own films! This always proves to be a great success among the members as all ideas and directions come from the members themselves. There are definitely some up and coming Spielbergs and Colin Farrells amongst us!

On Tuesday, some members decided a little retail therapy was needed and headed to Enniskillen to do some shopping, while others stayed at the centre and took part in activities such as orienteering and swimming. A table quiz took place that night and the competition was huge, but Team Jimbo's were the ones who stole first prize.

It was our final full day together at Share, some members headed to Enniskillen to shop some more while others took to the cruise around the lakes taking in all the sights!! We gathered in the big hall that evening where we had our movie premiere, our films had been edited and we were on the big screen! Some great laughs were had by all during our preview! Next everyone gathered outside for a barbeque, and off we went to prepare for the farewell disco that night. After lots of hair gel, straighteners, curlers and make-up, everyone was ready and a great night was had by all.

Sadly we had to say our goodbyes on Thursday and return home but we were leaving with lots of great memories. A big thank you to all members who attended, the staff of Share Village who were fantastic, and to all helpers for making it possible. What a brilliant week!!

Ciara Kelly
Youth/Respite Worker
Southern Region

Other Camp Dates

The May Adult Camp actually took place at the time of printing, from 18th May – 21st May in Cuisle Holiday Centre, Donamon, Co. Roscommon (we will have a full report in the next issue).

The July Camp for younger members is now scheduled from the 23rd July – 29th July and will take place in Ti Chulainn Cultural Activity Centre, An Mullach Ban, Co. Armagh, website www.tichulainn.com

News from the West!

Hi Everyone,

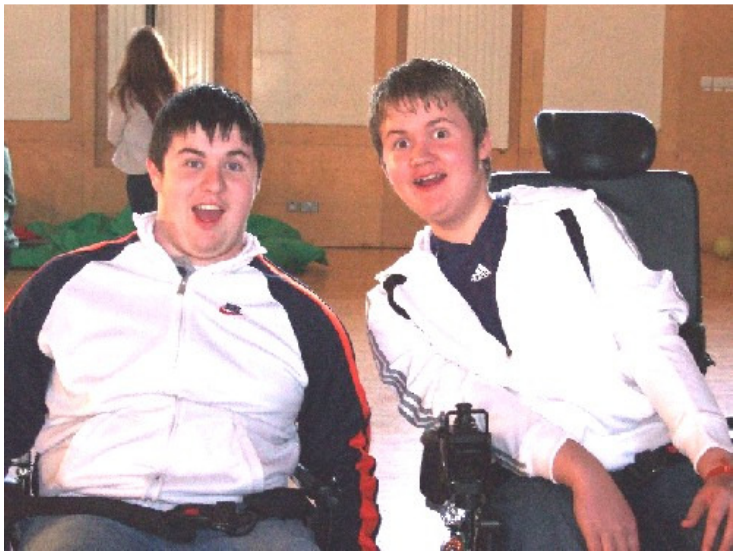
Just a Quick note to say that there is a LikoLight hoist available to all members in the West. The hoist is stored in the Galway office, if you ever need it just give me a call on 086 389 9286.

Also, MDI would like to congratulate Eileen Gormley (Galway) on her nomination for a Junior Chamber Ireland Top Young Person of the Year Award in Galway. Eileen has been nominated in the personal improvement/accomplishments category and her big night is Fri 25th May, we've got our fingers crossed for you Eileen! Good Luck!

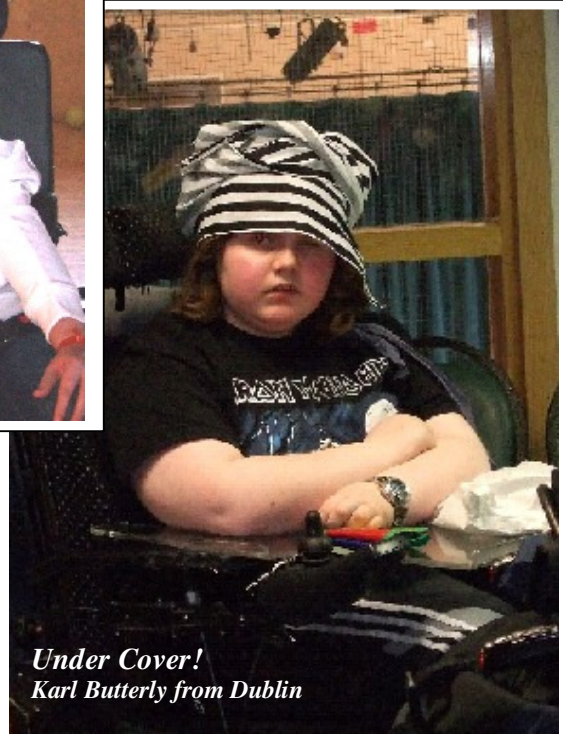
Aisling Dermody
Youth/Respite Worker
Western Region

Photos from MDI Youth Camp

Fermanagh - 31st March – 5th April 2007



Pictured left: *Daniel Stack & Patrick Flanagan (both from Kerry) sharing a joke on camp in Fermanagh*



Under Cover!
Karl Butterly from Dublin

Cork MDI Member, Brian Daly pictured with Margueritte Walsh (MDI Care Worker)

Below: *Sean McGonigle (Dublin) & Daniel Stack (Kerry) with MDI Driver from Cork, Jim O'Donovan.*

Left Photo: Grace Everett (Louth) & Helena Reilly (Meath) pictured on camp with MDI Youth Worker Emma Carass, centre.

Dublin Port Tunnel
Free Passage for Disabled Motorists

In recent months, some MDI members (who have their own specially adopted wheelchair accessible transport) have asked me to enquire as to whether they are exempt from toll charges through the recently opened Dublin Port Tunnel. These queries came about after it was noticed that the current "tunnel by laws" stated that classes of Vehicles and Users exempt from tolls include: *"Specially adapted Vehicles* ***driven*** *by disabled persons"*.

After some investigation and recent consultations with a fellow disability activist who contacted the National Roads Authority we can confirm that it is NRA policy to grant exempt passage through the Dublin Port Tunnel to disabled persons in specially adapted vehicles. This is whether the disabled person is driving or a passenger in the specially adapted vehicle. Identification cards for disabled drivers or disabled passengers issued by the Dublin Port Tunnel or by other Toll Road Operators will be accepted as valid forms of identification at the Dublin Port Tunnel.

The NRA have advised us that it was never their intention to exclude disabled passengers (with a valid Disabled Passengers toll card) from free passage through the Dublin Port Tunnel, or indeed any other toll plazas where this toll card is accepted. They have also confirmed that they will speak with all toll operators about the granting of free passage to disabled motorists who produce a valid disabled person's toll card (irrespective of whether or not they are the driver). We have also been advised that the wording of the relevant " by laws" relating to new projects will be formulated in a way that clarifies the position of disabled passengers in specially adopted vehicles, which in turn will avoid confusion in the future.

We thank the N.R.A. for their courtesy, co operation and clarification on this matter.

Hubert McCormack

Rural Accessible Transport Details

Below is a list of groups that provides wheelchair accessible transport in rural areas. Given the difficulties many members face regarding transport, we thought that you might find this useful.
This information was taken from Pobal's website, whose mission is to promote social inclusion, reconciliation and equality through integrated social and economic development within communities. Pobal is a not-for-profit company with charitable status. For more information log on to http://www.pobal.ie

Group Name	Telephone	E-Mail
Borrisokane Area Rural Transport Project, Tipperary	Tel: 067 27088	lmduddy@eircom.net
Clare Accessible Transport	Tel: 061 92431	ecatfeakle@eircom.net
Kerry Community Transport Ltd	Tel: 066 7147002	alan@kerrytransport.ie
Laois Transport for Rural Integration Programme Ltd	Tel: 057 8648699	laoistrip@eircom.net
Meath Accessible Transport Project Ltd	Tel: 046 9074830	meathtransport@eircom.net
North Fingal Rural Transport Company Ltd., Dublin	Tel: 01 8078855	northfingal@eircom.net
Offaly and Kildare Community Transport Ltd	Tel: 045 528124	okbus@oktransport.com
Carlow, Kilkenny & South Tipperary South Riding Rural Transport Ltd	Tel: 056 7790260	ringalink@eircom.net
County Limerick and North Cork Transport Group Ltd	Tel: 069 78040	chris@ruralbus.com
South Kildare Community Transport Ltd	Tel: 045-895450	kennolan@thekcp.ie
South Westmeath Rural Transport Association Ltd	Tel: 090 6448670	swrta@eircom.net
West Cork Rural Transport	Tel: 027 52727	David@ruraltransport.ie

Sky High for MDI!

Jason takes a "leap of faith" for MDI!

MDI would like to thank Jason Powis from Kilkenny (an employee of OKI Printing Solutions Ireland), for sky diving from 15,000 feet on 28th April to raise funds for MDI. Jason, who was cheered on by his children Natasha and Aarron (pictured below) hopes to raise over €1000. Proceeds will be divided between MDI and the Laura Lynn Hospice.

Jason, with his children Natasha & Aarron

A big "thank you" also to everyone who sponsored Jason, the staff and customers at OKI and Bank of Ireland and particularly Gavin, who helped raise the profile for Jason. Thanks also to Bank of Ireland and Jim Doyle in OKI for agreeing to match monies raised.

On behalf of MDI and Jane & Brendan at the Laura Lynn Hospice, I would simply like to say "thank you **Mr. Bond!"**

Jill Millar
MDI Member – Dublin

On Your Bike!

Hi All

My name is Mark Warner. I have a very close family member, Eoghan who has muscular dystrophy. Eoghan lives in Dumbarton (Scotland) and is a fantastic young man

On Saturday 26th of May, myself and my good friend Jay Graham will be riding our bikes from Dublin to Dumbarton (Ireland to Scotland) hoping to cover the 200 miles to reach our destination by Friday 1st June. We want to raise awareness and much needed money so that boys like Eoghan have a better future and quality of life.

Both of us are funding the trip (flights, ferry, accommodation etc) ourselves , or with the much appreciated assistance of Muscular Dystrophy members so all the money raised goes directly to Muscular Dystrophy Ireland and Muscular Dystrophy Campaign (UK) depending where the money is donated from. Our legs will be aching, our bums sore, our hands blistered!! So please help us with as much or as little as you can afford via our website or through Muscular Dystrophy Ireland. You can read more about our trip on www.justgiving.com/cycledublin

Many thanks for your support.

Mark Warner and Jay Graham

Respite Centre Questionnaire

In the last few weeks, all individuals on our database living with a neuromuscular condition should have received a questionnaire about 'centre-based' respite. The purpose of this questionnaire is to establish the needs and wants of you the member with regard to Respite Services, in particular 'Centre-Based Respite'.

This research project, which is being conducted by MDI, in partnership with the Irish Association for Spina Bifida & Hydrocephalus (IASBAH) and Friedreichs Ataxia Society Ireland (FASI) will provide a good opportunity for MDI to comprehensively establish its members needs in this area. A high response rate to this survey is essential in order achieve this and we would therefore encourage all members who haven't completed this questionnaire to do so. Please be assured that your anonymity will be guaranteed at all times.

MDI would like to thank Hugh Kane from the HSE (East Coast Area) for financial support with this project, Kate Power (MDI Respite Co-ordinator), George Kenny (IASBAH), Barbara Flynn (FASI) and Nuala Crowe (Independent Researcher) for all their hard work with regards to this project.

And finally, we would like to thank all members who took the time to complete this questionnaire (or are about to!). Without your input, we can not proceed!

Joe Mooney
Director – MDI

Congratulations

MDI would like to congratulate Lisa Fenwick, FSW (Western Region) on the birth of her new baby boy, James. We wish Lisa, her husband Joe and baby James every good wish in the future.

Letter of Appreciation

Below is a letter which was sent into us recently by one of our members who asked us if we would include it in our next newsletter. The letter speaks for itself!

To: Kate Power,
Respite Co-ordinator,
Muscular Dystrophy Ireland

3rd May 2007

Dear Kate and all at MDI.

I write this letter to let you all know that, thanks to our nursing supports funded by MDI, we have been out for a meal as a couple for the first time in four years. We recently went out to celebrate my Husband Ray's birthday, and one of our nurses cared for Andrew.

This would not have been possible without the funding from MDI. For many people this is something they can enjoy frequently, but for parents who provide full time care for a child it is not possible without supports.

We are truly grateful to MDI for providing the funding for relief nurses to care for Andrew. Once again many thanks to all involved, this service has made a huge difference in our lives.

Kind regards,

The Moore family.
Co. Laois.