



MDI News Update



Two monthly newsletter – July/August 2006, Issue 30

Muscular Dystrophy Ireland, 71/72 North Brunswick Street, Dublin 7.
Ph: 01 8721501 / 872 3826 Email: info@mdi.ie Website: www.mdi.ie

Editorial

Hello again,

Hope you all had a nice summer. The great weather certainly contributed to the success of the MDI youth camp in Fermanagh which took place from 14th – 20th July. With plenty of adventurous activities organised (see photos) the week proved very popular with the 22 young members who attended.

The “Research” section on page 2 gives details on how to obtain the latest reviews concerning exon skipping, which will interest families affected by Duchenne muscular dystrophy. Also on page 2 you will find details of a series of information evenings which MDI is organising to introduce a new Information Booklet.

Page 3 gives details on VAT refunds on aids & appliances for people with disabilities, which some members may not be aware of.



MDI Member Robert Quinn (centre) Go-Karting with the help of Kate Power and Caroline Moore at the MDI summer camp in Fermanagh last July.



MDI members speed boating, while on camp in Fermanagh in July.

Lisa Fenwick, the replacement Family Support Worker for Caroline Moran (who is on Maternity Leave) introduces herself on page 4. We would like to wish Lisa well in her new post. Also on pages 4 and 5 are details of Branch News.

Pages 6 to 8 gives details of various studies, programmes, courses and employment opportunities which are taking place and may be of interest to members.

I hope there is something of interest for everyone in this newsletter. I would however, encourage branches and members to send in contributions for future issues. Remember, this is an MDI members' newsletter, so why not share your experiences and voice your opinions and make the newsletter yours! Articles, photos etc. for the next issue should be submitted before Friday 20th October 2006. So, get writing and until then take care.

Hubert McCormack
Editor



Research Review Exon Skipping

Dr. Guenter Scheuerbrandt produces regular reviews of research into Duchenne muscular dystrophy, and his most recent review concerns exon skipping.

At the end of this year's annual meeting of the American Parent Project in Cincinnati, Ohio, 13 - 16 July, Dr. Scheuerbrandt recorded an interview with Professor Steve Wilton of the University of Western Australia mainly about exon skipping, the technique which it is hoped, will be able to change the fast Duchenne into the much slower Becker dystrophy within the not too distant future. The original text of the interview was shortened and edited and then approved by Professor Wilton to be distributed to Duchenne families and their care givers.

You can read this review online at:

http://www.parentprojectmd.org/site/DocServer/wilton_interview.pdf?docID=1161

or alternatively please call me on 01 8721501 or email karen@mdi.ie and I will send you out a hard copy. You can also find other articles by Dr. Scheuerbrandt at: www.duchenne-research.com

*Karen Pickering
Information Officer*

MDI Christmas Cards 2006

Sorry for mentioning Christmas already folks, but just let you know that this year's MDI Christmas Cards will be available from early October. We have 12 new designs this year (which you can view on our website [www.mdi.ie] soon). Cards will be sold in packs of 12 for €7. To order contact Steven Valentine on (01) 8721501 or email steven@mdi.ie

MDI Information Evenings for Members

MDI has produced a new booklet for members, which is a comprehensive guide to the services provided by MDI. The aim is for all members to know what services they may be entitled to, and how they can access these services. To introduce the new booklet, a series of information evenings will be held in the coming months, and members are welcome to attend the evening of their choice. As well as a guide to services, the evenings will also involve a presentation on the structure of the organisation.

The evenings will be held in:

- Heritage Hotel, Portlaoise:
Wednesday 20th September 2006
- Four Seasons Hotel, Monaghan:
Wednesday 27th September 2006
- Castle Hotel, Macroom, Cork:
Wednesday 4th October 2006

If you would like more information, please contact Karen Pickering on 01 8721501 or email karen@mdi.ie

If you would like to attend, please call or email to confirm what evening you will be attending and how many people will be going.



VAT refunds on aids & appliances used by people with disabilities

Information

If you live in Ireland and have a disability and as a result, need to use certain aids and appliances, you can avail of a refund of Value-Added Tax (VAT). People with both physical and mental disabilities can avail of these VAT refunds.

Rules

Aids and appliances for which a VAT refund may be claimed are aids and appliances that help you overcome your disability in the work place or with daily activities.

The aid or appliance must be owned by and for the exclusive use of the person with the disability. If the VAT refund is being sought by a person other than the user of the aid or appliance, the Revenue Commissioners may demand evidence that the aid is solely owned by and for the sole use of the person with the disability.

Examples of eligible aids and appliances include:

- Walk-in baths designed for people with disabilities
- Commode chairs
- Lifting seats and specified chairs designed for people with disabilities
- Tele-text
- Braille books
- Hoists and lifts designed for people with disabilities, including stair lifts.

It may be necessary to produce medical evidence of person's disability.

VAT refunds are **not** allowed on:

- Services for people with disabilities
- Rented aids and appliances
- Cars / Vans for disabled drivers and disabled passengers - VAT refunds on these items may be claimed by contacting the Central Repayments Section, Customs

and Excise, Coolshannagh, Co. Monaghan, Tel: (047) 82800 or LoCall: 1890 60 60 61.

- Radios for the blind - VAT items on these items may be claimed by filling out Claim Form VAT 59, which is available from the VAT (Unregistered) Repayments Section, Kilrush Road, Ennis, Co. Clare, Tel: (065) 684 9000 or LoCall: 1890 20 20 33, Fax: (065) 684 9248, e-mail: unregvat@revenue.ie.

How to apply

You can download Claim Form VAT 61A at: <http://www.revenue.ie/forms/vat61a.pdf> Before you submit your claim, you should make sure that:

- You have completed sections 1-3, including signing the declaration in section 3 in your correct status
- You have attached every piece of supporting documentation, i.e., original invoices for all the goods in the claim or, in the case of imported good, receipts for VAT paid at importation. In the case of a hire purchase agreement, you will need to supply a copy of the agreement, together with the invoice.
- The invoices you are supplying are legible, dated and display the VAT content; the supplier's name, address and VAT number and an adequate description of the goods in question.

You must make your claim within six years from the end of the taxable period to which the claim relates. Taxable periods within each year are:

January/February	March/April
May/June	July/August
September/October	November/December

For example, a claim made in respect of an invoice issued in January 2000 must be made no later than February 2006.

Where to apply

VAT (Unregistered) Repayments Section
 Revenue Commissioners
 Kilrush Road, Ennis, Co. Clare
 LoCall: 1890 20 20 33
 Fax: (065) 684 9248
 E-mail: unregvat@revenue.ie

*This document was printed from the Oasis website
(<http://www.oasis.gov.ie/>).*



New Staff Member

Hi!

I'm Lisa Fenwick and am covering Caroline Moran's maternity leave in the West and Midlands regions covering Galway, Mayo, Roscommon, Westmeath,



Lisa Fenwick

Offaly and Longford. I am originally from Birmingham in England, home of the Balti for all those who like a good curry. I have been living in Galway for the last 7 years and absolutely love it.

My background is in social care work where I have worked in a variety of roles including residential and homeless services. I have lots of experience of advocating for people with disabilities with services such as government and voluntary agencies.

I have been fortunate enough to visit some wonderful members of MDI and I would like to thank you all for your kind hospitality. Thanks also for your patience with directions - I'll know every road and breen in the West and Midlands! I am looking forward to meeting all the members in the area over the next few months. I am working part-time hours from Monday to Wednesday. Please feel free to contact me on 086 6066106 or 091 583890 or email: lisa@mdi.ie

I would like to take this opportunity to wish Caroline Moran and her family all the very best with their new daughter, Hannah. I know many of our members would also like to pass on their good wishes.

Lisa Fenwick

MDI South East Branch News

Weekend Break

On Friday 30th June 2006 members of South East Branch went away to Killarney for a three night break. We stayed in Lakeland Cottages which were a great facility and were within easy reach of the wonderful amenities of Killarney. During the day we enjoyed shopping, boat trips, a trip around the Gap of Dunloe, and a visit to Muckross House. On the last night we enjoyed a party in one of the cottages with lots of dancing and a sing song. The good weather was an added bonus and contributed to a great weekend that was had by all.

Christmas Party

We would also like to remind members of the South East Branch that this years Christmas party will be held on Wednesday 13th December. If you are interested in attending we would ask you to pass on your name to Mary on 086 3023547 or Linda on 087 9639438. We hope to see you all there!

*Christine McDonald
South East Branch*

For Sale

Volkswagen Carravelle 04 Reg,
24,000 miles. 1.9 Diesel, Black,
Air Conditioning,
Wheelchair Accessible via
Portable Ramp.
Asking Price €33,000
Phone: 087 6822214



Lucan Golf Club Raise €4,000.00 for MDI

Muscular Dystrophy Ireland (MDI) would like to thank Lady Captain Maura Coffey and all the members of the Lucan Golf Club who recently organised a very successful Charity Day & Bumper Raffle which took place on Friday 21st July 2006. A very enjoyable evening was had by everyone who attended and over €4,000.00 was raised for MDI. We would also like to thank everyone associated with the Lucan Golf Club who donated raffle prizes and/or bought tickets or supported this event in any way. Your support is much appreciated.



Lady Captain Maura from Lucan Golf Club presents Florence Dougall, (Chairperson of MDI) with a cheque for €4,000.00

MDI North West Branch

The MDI North West Branch would like to remind its members that it has a wheelchair accessible minibus based at Roy Wilkie's, Ballyholey, Raphoe which is available to members in Donegal, Sligo and Leitrim. Below is a group of MDI Members being instructed on how to operate the lift equipment etc on the bus; L-R Eddie Duffy (Instructor from Parfit, Dublin), Alice Kelly (Letterkenny), Sharon Roulston (Newtowncunningham), Matt and Susan Peoples (Kerrykeel). *Photo Gertrude Colhoun.*





Martin O'Donoghue Remembered

The following article was submitted to us by the parents of the late Martin O'Donoghue, who asked us if we would include it in our newsletter. MDI would like to extend our condolences to the O'Donoghue family on their sad loss.

Martin O'Donoghue from Tubber, Co. Clare had myotonic dystrophy but had a very fulfilling life.

At his funeral on 15th July 2006, the local priest Fr Brian Geoghan described Martin as the teacher who taught love to his friends and neighbours.

His carers were Deirdre (his teacher), Noeleen (his bus driver) and Michelle (his bus assistant)

He liked bowling and was an avid supporter of Cork hurling (his mother Rosarie is from Midleton). He also liked sports car races, bikers and videos.

Martin is a first cousin of Fiona O'Donoghue who works in the MDI Head Office in Dublin. He will be sadly missed by his family and his school pals in St Clares, Ennis.

Written by Leo O' Donoghue



Martin (centre) with his parents, Leo and Rosarie and sisters Leona and Dervela.

Study Initiated to Identify Impact of Disability at Farm Level



Teagasc have initiated a study examining the impact of disability among farmers in Ireland. The study follows recent CSO data, which shows that the agriculture, forestry and fishing sectors report the highest level of disability relative to any other.

The study will be conducted by Mr. Shane Whelan at University College Dublin (UCD). Shane, who comes from a farming background in Co. Wicklow, decided to conduct the study after he became aware of a number of farmers in his home area who acquired a disability.

Disability among farmers could be from any cause including farm and non-farm accidents or health related conditions.

Shane would really appreciate making contact with any farmer who reports a disability, to address issues that they might have at a practical level. If you require further information, or are interested in participating in this study please contact Shane at 087 6739212 or shane.g.whelan@ucd.ie.



VALUING YOUR VOICE

**THE CHILDCARE INCLUSION PROGRAMME IN DESSA
(Disability Equality Specialist Support Agency),
PLAYWORKS.uk & ALISON JOHN ASSOCIATES
WOULD LIKE TO INVITE FAMILIES WHO HAVE
EXPERIENCED DISABILITY TO ATTEND A CONSULTATION**

ON

SATURDAY 16TH SEPTEMBER

FROM

2.30P.M. TO 4.30 P.M.

AT

**THE ARK CULTURAL CENTRE FOR CHILDREN
EUSTACE STREET, TEMPLE BAR, DUBLIN 2**

***WE WANT TO ENSURE THAT THE VOICES AND
EXPERIENCES OF DISABLED CHILDREN AND YOUNG PEOPLE
AND THEIR PARENTS ARE
REFLECTED IN OUR INCLUSIVE PLAY TRAINING
FOR CHILDCARE AND PLAY PROVIDERS.***

***THIS IS AN OPPORTUNITY FOR CHILDREN, YOUNG PEOPLE AND
PARENTS TO HAVE A SAY IN A FUN AND INTERESTING WAY,
SO WE LOOK FORWARD TO SEEING YOU THERE!***

**FOR MORE INFORMATION OR TO ACCEPT OUR INVITATION
CONTACT THE CHILDCARE INCLUSION PROGRAMME**

01 4536864

cip@dessa.ie



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**The Center for
Independent Living
Carmichael House**

NUI Maynooth Certificate in Disability Studies

About the Course

The course provides a platform for the discussion and development of disability issues in Ireland. This Certificate is based upon the philosophy of Independent Living, and seeks to advance the Social Model of disability, which is increasingly seen as best practice in the development of policy and the provision of services for people with disabilities.

Course Aims

- To examine theoretical perspectives of disability
- To develop the Independent Living Philosophy
- To examine a rights based approach to Disability

Course Content

Module 1:	Student Support & Study Skills
Module 2:	Models of Disability
Module 3:	Equality & Advocacy
Module 4:	Social Analysis & Environment
Elective:	Sexuality & Relationships

Admission Requirements

- Participants must be 23 years or older
- Experience of working in the field of disability
- Have the skills to participate fully in the NUI Maynooth Certificate Course
- Openness to reflect upon one's own practice, attitudes & beliefs
- Commitment to working in a group setting

Course Duration

100 hours part time.
From September 2006 - May 2007.

Fees €950

Location

Dublin – venue to be confirmed

Applications

Contact Sarah Dixon at CIL, Carmichael House for application forms, before 7 September 2006 Telephone 01 8730 455
Email sarahdixon@dublincil.org

Enrolment – September 2006

Are you a disabled person looking for work?

**Interested in a career in Finance,
Business Development or Consumer
Sales?**

Our client is currently offering positions to candidates keen to develop a career in the following positions:

**Revenue Assurance, Financial Analysis
Administrator, Business Development
Executive, Finance Support, Consumer
Sales**

The ideal candidate should have:

- Third level education or equivalent experience
- Proven experience in Microsoft word, excel and the internet
- Strong communication and presentation skills
- Highly motivated
- Ability to work to deadlines

Duties and responsibilities:

- This will vary for each position

This is an excellent opportunity for you to develop your career with one of Ireland's leading edge organisations.

Interested candidates should contact Louise Milicevic on 01 2057 306 for a confidential discussion. You may also post your CV to: Louise Milicevic, Access Ability, Gandon Villa

Rosyln Park, Sandymount. Dublin 4
Alternatively email your CV to
louise.milicevic@accessability.ie