Alan’s Mizen to Malin Skateboard Challenge raises over €10,000 for MD

MDI member Naglis Montvilašius pictured with Ronan Collins (from RTE) and Alan Collins (Ronan’s nephew), who “put the boot to the board” and skateboarded from Mizen Head to Malin Head in July and raised over €10,000 for MDI. What a great achievement. For more details see page 8.
Duchenne muscular dystrophy (DMD) is the most frequent neuromuscular disorder of childhood. Although DMD is primarily classified as a skeletal muscle disease, cardiac complications play an important role in the course of this inherited disorder. In addition, not all subtypes of muscles are affected in the same way.

While extremities and trunk muscles are drastically weakened, extraocular muscles are usually spared in Duchenne patients. In order to determine the global protein expression pattern in these differentially affected muscles, the Muscle Biology Laboratory, NUI Maynooth has performed an MDI-funded comparative study of the established mdx mouse model of DMD.

The laboratory of Prof. Kay Ohlendieck used an advanced detection method called proteomics, which separates and analyses thousands of protein components of a muscle cell and then identifies proteins with an abnormal density by mass spectrometry. In agreement with the varying degrees of muscle degeneration, proteomic profiling clearly showed that several-fold more proteins are negatively affected in severely dystrophic diaphragm and heart muscles as compared to naturally protected extraocular fibres. Out of 2,500 detectable proteins, approximately 80 changed proteins were identified in the heart, but only 7 altered protein species in extraocular muscle preparations. Thus, the lack of the protein dystrophin triggers a generally perturbed protein expression pattern in the heart, affecting especially energy metabolism and contractile strength.

These biochemical abnormalities probably play a key role in cardiomyopathic side effects. The majority of DMD patients develop clinical cardiac symptoms during the second decade of life, including arrhythmias, cardiomyopathy and regional wall abnormalities, leading to severe cardiac complications in about 20% of cases.

On the cellular level, the gradual replacement of cardiac fibres by connective tissue is a hallmark of the dystrophic heart. In contrast, the unaffected extraocular muscle system exhibits a near normal cohort of expressed protein. The establishment of the molecular differences between the two muscle types has established a large number of novel biomarkers. These protein candidates will now be used to identify new therapeutic targets, further our biomedical understanding on disease progression and can also be used to improve diagnostic procedures.

The following peer-reviewed scientific papers have been published during this research project and the funding of MDI has been acknowledged:


For any questions, please contact:
Prof. Kay Ohlendieck,
Department of Biology, NUI Maynooth,
E-mail: Kay.Ohlendieck@nuim.ie; Tel. 01-7083842.

Illustration: Fluorescent labeling of dystrophin, the protein that is severely affected in Duchenne muscular dystrophy, in heart muscle. The protein is almost exclusively located in the surface membrane system where it stabilizes the muscle cell during cycles of contraction and relaxation.
Europlan Conference

As an active member of the Genetic and Rare Disorders Organisation, MDI supports the Government’s commitment to developing a National Plan for Rare Diseases by 2013. As a starting point for formulating this plan, EU member states are holding conferences over the next 5 months to look at the current situation and identify how to improve diagnosis, care, research and access to treatments for people with rare diseases. I am a patient group representative on the Irish Europlan organising committee, which is comprised of representatives from other patient groups, clinicians, science and industry and will also have government representation. The Irish conference will take place on Friday 3rd December in Dublin Castle and will be open to all interested groups including people with rare conditions and their families. Further details and an agenda will be available soon.

Karen Pickering

Date for Your Diary

SMA Information Day

An information day for people with spinal muscular atrophy will be held on Saturday 2nd October 2010 in Dublin. Further details will be confirmed in due course.

MDI AGM Speakers

MDI’s AGM was held on Saturday 24th April 2010. Prior to the AGM there was an information session with very interesting presentations on MDI-funded research in the CRC in Dublin and University College Cork, and payments for people with disabilities and their families from the Dept. of Social and Family Affairs. Thank you to all the speakers who gave their time and expertise on this day. A report on the information session is being circulated to members of MDI with this newsletter. If for any reason you have not received this report and would like to, please contact Karen Pickering, Information Officer on 01 8721501 or email karen@mdi.ie
Some tax-free credits and allowances are intended especially for people with certain disabilities. Some features of the income tax code are also of particular interest.

General information on Income Tax

The tax year is the same as the calendar year. It runs from 1 January to 31 December each year. The standard rate of income tax is 20%. Depending on your circumstances, you may have to pay income tax at the higher rate of 41% on some of your income.

Income from virtually all sources is taxable. This includes long-term social welfare payments such as Invalidity Pension, Blind Pension, Carer’s Allowance and Carer’s Benefit. Illness Benefit and Jobseeker’s Benefit are also taxable.

Certain types of income are exempt from tax. The increase for qualified children, paid with Illness Benefit and Jobseeker’s Benefit, and the first €13 per week of Jobseeker’s Benefit are exempt, as is the first six weeks of Illness Benefit in a tax year. Jobseeker’s Benefit paid to systematic short-time workers is also exempt from tax.

Other tax-exempt payments are Disability Allowance, Maternity Benefit, compensation for personal injuries (the income arising from it may also be exempt from tax if specific conditions are met), statutory redundancy lump sums, certain payments in compensation for loss of employment, Hepatitis C and HIV compensation awards, compensation payments to Thalidomide victims, some military pensions, compensation paid to people who were abused in residential institutions and compensation paid to people who were illegally charged long-stay charges in nursing homes.

Even if your social welfare payment is deemed taxable, if it is your only income you are unlikely to be liable to pay any tax. If you have a social welfare payment and another source of income, you may have to pay tax on it.

The income levy

An income levy was introduced from 1 January 2009. It is calculated separately from income tax: it is charged on your gross income, before deductions such as contributions to pensions are taken into account. You cannot claim deductions or credits to reduce the amount of levy you must pay. Similarly, excess or unused tax credits cannot be used to reduce your liability to the levy.

You are not liable to pay the levy if your income is less than €289 per week (€352 per week before 1 May 2009). Social welfare payments and Health Service Executive payments are not taken into account. You do not pay the income levy if you have a medical card.

Income tax reliefs

Tax reliefs reduce the amount of income tax that you have to pay. The tax reliefs to which you are entitled depend on your personal circumstances. The two main types of income tax relief are tax credits and tax allowances.

Tax is calculated as a percentage of your income. Tax credits are deducted from this to give the amount of tax that you actually have to pay. A tax credit has the effect of reducing your tax liability by the amount of the credit.

The value of a tax allowance depends on the highest rate of income tax that you pay. Take the example of a tax allowance of €100. If you pay tax at 41%, then a tax allowance of €100 will apply at the rate of 41% and reduce your tax by €41 (€100 x 41%). If the highest rate of tax that you pay is 20% then the same tax allowance of €100 will reduce your tax by €20 (€100 x 20%).

Tax exemption limits

If you are aged over 65, tax exemption limits apply. If your income is below the limits you are not liable for tax. They are not the same as credits or allowances. If your income is just slightly above the limit, you may get marginal relief. This means that you pay tax at 40% on the part of your income that exceeds the exemption limits. The tax exemption limits from January 2009 are €20,000 for a single or widowed person and €40,000 for a married couple.
These limits are increased if you have dependent children: by €575 each for the first and second child and by €830 for each subsequent child. For tax purposes, a child is a dependant if he or she is aged under 16, or over 16 and in full-time education or in training as an apprentice, or has become incapacitated before reaching the age of 21 or before finishing full-time education.

The Main Disability-Related Tax Reliefs

Blind Person’s Tax Credit
A person who is blind is entitled to an extra tax credit of €1,830. For a married couple where both are blind, the extra tax credit is €3,660.

Guide Dog Allowance
A tax allowance of €825 is given annually if you or your spouse has a guide dog and you are a registered owner with the Irish Guide Dog Association (relief applies at your top rate of tax).

Incapacitated Child Tax Credit
This tax credit of €3,660 can be claimed by a parent or guardian of a child who became permanently incapacitated before the age of 21, or while she or he was in full-time education. Where there is more than one such child, the tax credit may be claimed for each child. The income of the child does not affect the credit.

Allowance for employing a carer
A tax allowance of up to €50,000 (at your top rate) is available where a person is employed to care for a person with a disability. This allowance may be claimed by one family member or divided among a number of family members if they are contributing towards the cost.

Home Carer’s Tax Credit
A tax credit of €900 is available for married couples (taxed jointly) where one spouse works in the home caring for a child for whom Child Benefit is being paid, a person over 65, or a person who requires the care because of a disability. The income of the carer must not exceed €5,080 in the tax year. A reduced tax credit is given where the income is between €5,080 and €6,880.

Dependent Relative Tax Credit
This tax credit of €80 is given to a taxpayer who maintains:
• A relative who has a disability or is aged 65 or over
• A widowed parent
• A son or daughter who lives with the taxpayer and on whom the taxpayer relies because of old age or infirmity.

No tax credit is given if the income of the relative is above €13,473.

Refunds of VAT
A refund of VAT (Value Added Tax) may be claimed for certain aids and appliances used by someone with a disability to assist them with independent living and working.

Age Tax Credit
In addition to the usual personal tax credits, people over the age of 65 are entitled to an Age Tax Credit. This tax credit is €325 for a single person and €650 for a married couple. In the case of a married couple, the credit is given where either spouse is over 65.

Bereavement credits
There are special tax credits in the five years following bereavement for widowed people with dependent children. There are also special rules governing taxation in the year of the bereavement and these apply whether or not there are dependent children.

Medical expenses
A tax relief at the standard rate is available for money spent on certain medical expenses. You may claim this relief if you pay the medical costs for yourself or any other person. (For expenses before 1 January 2009, relief was given at your highest rate of tax.)

The expenses for which the relief may be claimed include doctors’ bills, drugs, the supply and repair of medical and surgical appliances used on medical advice, and hospital and nursing home costs. Routine dental and ophthalmic expenses are excluded.

How to apply for relief on medical expenses
You should complete the claim form MED 1 at the end of the tax year. (You can download the form from the Revenue website at www.revenue.ie. Long-term care needs can be assessed by Revenue’s telephone number 1890 306 706.)

If you find that you have exceptionally large expenses throughout the year, you may be able to claim a refund quarterly.

No refund is given for expenses which you can claim from another source such as the Health Service Executive (HSE) or a private health insurance company.

Nursing home fees
Registered private nursing homes are approved by the Revenue Commissioners for the purposes of getting tax relief on fees paid. Your own tax office can tell you if a particular home is approved. This list of approved nursing homes is available on the Revenue website at www.revenue.ie. Long-stay charges paid to public hospitals and nursing homes also attract tax relief.

Tax relief is available to the resident, the resident’s spouse or any person who is paying the fees. Your local tax office can give you more information. Other expenses which may qualify for relief include employing a qualified nurse in case of serious illness, where recommended by a doctor.

Tax relief on Deposit Interest Retention Tax (DIRT)
If you have savings in a bank, building society or ordinary post office account, tax at 25% is deducted at source (increased from 23% since 8 April 2009). This is called De-
Interest Retention Tax (DIRT). If you or your spouse are permanently incapacitated or aged over 65 and exempt from tax because of your low income, you are not liable to pay DIRT.

The health levy
In addition to their PRSI payments, people between the ages of 16 and 70 may have to pay the health levy if their income is over €500 per week. Anyone over this limit is liable to pay the health levy at 4% (since 1 May 2009) on all of their income, but if you receive more than €75,036 per year, you pay 5% for the portion of your income over that amount.

Employed or retired people with income of less than €500 in any week are exempt from the contribution in that week. Income from social welfare payments is not counted when calculating your income for the health levy.

You do not have to pay the health levy if you are a medical card holder or you are getting Widow’s/Widower’s Pension, One-Parent Family Payment or Deserted Wife’s Benefit/Allowance.

Useful addresses

Revenue Commissioners
Dublin Region - Lo-call: 1890 333 425
South West Region - Lo-call: 1890 222 425
East and South East Region - Lo-call: 1890 444 425
Border Midlands and West Region - Lo-call: 1890 777 425

VAT Repayments Section
Government Buildings
Kilrush Road, Ennis, Co. Clare
Lo-call: 1890 202 033 - Website: www.revenue.ie

Department of Social and Family Affairs
Information Section
Lo-call: 1890 66 22 44 - Website: www.welfare.ie

International Conference on Technology and Disability

Respect is partnering with Michigan State University to host an International Conference on Technology and Disability on Saturday, 16 October, 2010 at Carton House Hotel, Maynooth, Co. Kildare.

The aim of the conference is to create awareness and to encourage thought provoking discussions on what is new in the world of technology and research, with the view to utilising these findings to improve the quality of life for those with disabilities.

To reserve your place or for further information about this conference visit the following website www.doctrid.com.

Emmaus Retreat & Conference Centre

Do you require a short break in relaxing surroundings or overnight wheelchair accessible accommodation in Dublin?

Emmaus Retreat & Conference Centre offers modern residential accommodation with 62 ensuite guest rooms (including four wheelchair accessible bedrooms) of the highest standard close to Dublin Airport. The Conference Venue and Meeting Rooms are equipped to facilitate the needs of modern technology.

Whether your requirements are for a school or adult retreat/programme, a corporate retreat or team building exercise, a religious congress or simply accommodation in a quality, relaxed and peaceful setting, prior/after a flight to/from Dublin Airport, at a competitive price – Emmaus are confident you will enjoy your stay at their Retreat & Conference Centre and return to visit again. Bed & Breakfast rates start from €40.00 for a single room and €30.00 per person sharing for a twin or double room.

For more information about the Emmaus Retreat & Conference Centre contact:

The Emmaus Centre, Ennis Lane, Lissenhall, Swords, Co Dublin.
Tel: 01-870 0050
Fax: 01-840 8248
Email: emmauscentre@emmauscentre.ie
Website: www.emmauscentre.ie
The Ireland Bike Fest is an international gathering for motorcycle owners, enthusiasts and anyone, young or old, with (or even without) an interest in bikes. This extremely popular event on the biking social calendar is totally free of charge, where one can bask in the glory of some slick, well-built machines, soak up the atmosphere and browse through the stalls in the bustling Bike Village, and enjoy free entertainment, fun and games for every member of the family.

The Ireland Bike Fest in Killarney has been growing from strength to strength each year and the 2010 event proved to be no exception. This year's event took place from 4th - 7th June 2010 (Bank Holiday Weekend) and as in previous years, the atmosphere was just as fantastic.

Muscular Dystrophy Ireland (MDI) has been proudly associated with this event since its conception in 2006, which has raised thousands of euro each year for MDI. And this year was no exception. We can now confirm that the total raised for this year's event was €21,400 which is fantastic. Although we were slightly disappointed that we didn't exceed last year's figure of €22,500, we still can't complain as it's been a very tough year for everyone and to achieve what we have done is excellent. This is a wonderful achievement and thanks to everyone concerned for all their hard work and support. MDI would especially like to thank: Eileen, Martina and Elaine Mayse, Brendan, Aisling and Emer McElligott, Jimmy, Margaret, Sam and Emma Murray, Siobhan and Nicholas Windle and everyone else who helped to sell tickets in Killarney and elsewhere, for a job well done.

MDI are also extremely grateful to both The Gleneagle Hotel in Killarney, Co Kerry and Harley Davidson Ireland who have been supporting us with our Awareness and Fundraising activities since 2006. We really appreciate being associated with this event and look forward to enjoying a continued and growing fundraising initiative together.

All proceeds from this event, as in previous years, will go towards the provision of holiday and respite support services for people with muscular dystrophy.

**Harley Davidson Bike Winner**
The Gleneagle Hotel and Harley Davidson Ireland once again organised for a Harley Davidson Bike to be raffled at the event, with all proceeds going to MDI. The draw took place on Sunday evening, 6th June 2010 and the lucky winner was John McKeon from Freemont, Co Cork. (pictured left centre) with Breffni Ingeron (Bike Fest Organiser) and Alan Shortt (Comedian / TV Presenter). Second prize went to: Tommy Peirce from Dunard, Co Wicklow and third Prize went to: Padraic O'Shea from Killarney, Co Kerry. Thank you to everyone who bought tickets and helped to make this event a huge success.
On the 10th of July 2010 Alan Collins set off on a skateboarding challenge of approximately 835km when he embarked on mission from Mizen Head to Malin Head to raise funds for research into treatments for children with Duchenne muscular dystrophy.

Alan has been skateboarding since he was 9 years old and has a real passion for skateboarding. He said the thought of children not being able to enjoy what they love made him want to raise money and awareness for muscular dystrophy.

Alan’s uncle, Ronan Collins from RTE, lent his support to his nephew when he participated in a photo shoot along with 8 year old MDI member Naglis Montvilas to help publicise this event prior to Alan’s adventure (see front cover). Thanks Ronan and Naglis for this!

Alan “put the boot to the board” and commenced this skateboarding challenge on Saturday the 10th July at Mizen where MDI Cork member Brian Young (8) and his family showed their support and sent him skating!!!

Alan completed this challenge on 20th July at 4pm when he rolled into Malin and was met by family, friends and representatives from MDI. This was an amazing achievement and Alan has so far has raised over €10,000 for MDI which is absolutely fantastic. You can still support Alan, by donating via the MDI website on: www.mdi.ie.

MDI would like to sincerely thank Alan (literally) for all his hard efforts and for raising both funds and awareness for muscular dystrophy. It was really appreciated and congratulations on a magnificent achievement. Well done and thanks again!

The following summary of Al’s adventure was taken from his blog (http://skatinmizenmalin.blogspot.com/)

Day 1 - Mizen to Glengarrif
Day one of Al’s Mizen to Malin challange was marked by some delicious Irish summer weather and the big boy lapped it up. Puddles, potholes and rusty bearings, were ignored as plenty of well wishers beeped on the challenge. Thanks to Liz and Brian Young (pictured above with me) who helped kick us off at Mizen head in dour conditions and then caught up for some donation collections along the way.

Day 2 - Glengarriff to Killarney
Day two's weather may have been a little kinder, but the gritty gravelly hills sure were not. Once again, Al soldiered on through steep terrain including Caha Pass and Mole's gap through the ring of Kerry. People again showed great support and even threw us some free grub, bonus! Al reached Killarney and even reached a top speed of 45kmph on the rattling downhill, aw yeah!

Day 3 - Killareny to Kilrush.
Day three provided the longest stage so far, but on far flatter terrain as Al pushed through 90kms of County Kerry's roads, leaving Killarney, passing through Tralee, up to Tarbert and eventually stopping in Kilrush right before the skies opened up- perfect timing as the weather was kind to us all day.

Day 4 - Killrush to Ballyvaughan
Day four was a big race against time- we started early to avoid the impending rain, and although Al covered over 30km of dry rocky road, the downpour eventually caught up with him. Nonetheless, Al trudges on through Lehinch, Lisdoonvarna and the tip of the Burren to cover a good 90 km in eventually sopping wet pot holed conditions. He even encountered the dreaded corkscrew hill in horrible conditions and came away unscathed... "roll on day five"
Day 5 - Ballyvaughan to Oughterard
Day five saw us leaving the epic landscape of The Burren Co. Clare where Al was greeted with a strange warm sensation upon his skin...oh yeah, the sun! It was the first time Al got to get his solar panels out on the whole trip, but alas his sun break was short lived. A torrential waterfall opened upon entry to Galway city and once again Bray's finest found himself trudging through puddles in his soggy gear- still though, another 90km was conquered and the usual double dinner was served up to the chunky one. Roll on day 6!

Day 6 - Oughterard to Letterfrack
We've had now roughly passed the halfway point of this epic journey and Al had finally started to display some mild signs of fatigue after six consecutive days of heavy mileage on his board. Although he was feeling a bit tired this did not seem to affect him too much as he finished ahead of his own gruelling schedule today as we left Oughterard and swung up through the heavy showery hills and scattered lakes of Connemara. After passing through Clifden, Al tore up the final section of the day on some slick and slippery downhills in Letterfrack where he cruised in with time to spare to appear on local radio. Roll on day seven!

Day 7 - Letterfrack to Mulranny
Now one solid week deep into Al's adventure and it was day seven that would throw up the toughest challenge yet. Al got rolling from Letterfrack Co. Galway and had a dream roll through a breathtakingly scenic fjord (Galway) where some of the country's finest scenery was accompanied by some very smooth road, plus a few short heavy showers for good measure. However, once Al crossed the county border in Mayo the road seemed to convert into rubble and the wind turned on his face, making the final 60 km of today very arduous. The big man was showing the struggle but never once gave up and hacked at an uphill finish in Mulranny Co. Mayo that left him hankering for a dip in Clew Bay. Legs are being rested and day eight is just around the corner!

Day 8 - Mulranny to Enniscrone
Eight straight days of Irish roads were definitely taking their toll on Al this morning as he forced his stiff pegs into gear this morning, departing from a most excellent B&B near Mulranny, Co. Mayo. Fortunately the Mayo roads did not punish Al like they had the previous day, and we even got a run of sunshine as the Bray man drifted along the open plains of Mayo. The finish line incentive seemed to liven his spirits as he finished strong and entered Co. Sligo to rest up in Enniscrone for the night. A Sligo filled day 9 is waiting for those legs tomorrow..

Day 9 - Enniscrone to Bundorren
Yesterday's gruelling start was a distant memory as on the ninth day of the trip the sun came out to play for a full day. Our finest day yet seemed to bring a new surge of energy to Al's stiffened pins as he ate up over 85kms of Sligo road, glancing through Leitrim and finishing up coast-side in sandy Bundorren, Co. Donegal. Road conditions were thankfully largely favourable, so the big man made the most of it and hacked in in good time. The penultimate day of this challenge is tomorrow, and with stiffening legs and forecast rain, day ten will be a tough one from Bundorren to Letterkenny.

Day 10 - Bundorren to Letterkenny
On the decade day of this trip Al was joined by some great support as he chomped up 84 kms of Donegal roads. Locals and neighbours chipped along and went as much distance as they could handle in a great show of support on this the penultimate day of Al's mission. The sun shone for the most part, but inevitably it rained, which just added a little spice to Al's 50kmph eye bleeding hillbomb on the outskirts of Donegal town. Ten amazing days down, just one more to go..

Day 11 - Letterkenny to Malin
The Mizen to Malin skate mission is complete! Al chomped through North Donegal's finest rolling hills to come in strong, even catching 53kmph on some very scenic downhills. Local skaters, family, friends and representatives from Muscular Dystrophy Ireland were on hand to give Al a warm welcome as he trudged through the final uphill struggle at Malin head. The opposite side of the country gave us the opposite weather conditions (despite the forecast) to the murky start in Mizen head as the sun split the stones on a fine Donegal day. Job very well done Al, put the feet up!

Don't forget you can still donate to Al's charity of choice Muscular Dystrophy Ireland by visiting www.mdi.ie
**Other Recent Fundraising Events**

**June / July 2010**

**Skydive**
In June, Joe Mooney CEO of MDI met with Karen Campbell (pictured right) to receive the tremendous amount of €6,250.00 which she raised by taking the plunge and facing her fears in a Sky Dive Parachute Jump on 21st May last, with all proceeds going to MDI.

Well done Karen. Your relentless fundraising efforts and bravery are sincerely appreciated by all the members and staff. Many thanks for your continued support.

**Raffle**
Many thanks to Veronica O'Reilly Manager of Pulse Accessories in Navan Shopping Centre who organised and hosted a raffle in store on Thursday the 10th June and raised €150 for MDI. Thanks also to Carol Cosgrove MDI member & Patricia Turner for their support with this event.

*(Pictured left are: Veronica O'Reilly & Patricia Turner fundraising for MDI)*

**Cycle - Lough Derg**
15 Cyclists took to the tar on the 12th of June and cycled over 70 miles around Lough Derg and through the beautiful Shannon region for MDI's respite support services and medical research fund. Over €3,466 was raised on the day. Many thanks again to all the volunteers, sponsors and cyclists. Fundraising is essential to enable MDI to continue providing essential respite support and funding medical research. Well done to all, here’s looking at Lough Derg Cycle 2011!!

**Cycle - West Cork**
Muscular Dystrophy Ireland staff and friends took part in the well organised 2010 West Cork Emergency Services Cycle in Skibbereen on Saturday the 10th July (38 Miles). MDI is one of the seven recipients for this cycle. Congratulations to all 290 cyclists who braved the weather and took part. The current monies raised are €32,000 and counting………

MDI would like to sincerely thank all who organised and sponsored the event, a truly tremendous day for all involved.

*In the picture left to right*  
Amy Bramley, Annemarie Raftice (Citco Cork) Kathleen Cummins & Kate Power
Upcoming Fundraising Events

Calling all dare devils: Anyone interested in WALKING ON FIRE for MDI??!!

Fire Walking is one of the “ultimate of fundraising challenges” and MDI is organising our first ever Fire Walk in a bid to raise much needed funds for respite support services and medical research. Numbers interested are still very low, so unfortunately this event is still pending and is scheduled to take place later this year but unless we get 30 brave participants or more we can not proceed with this event. If you are seriously interested please email amy@mdi.ie or phone Amy at 086 818 5352.

MDI Golf Classic
Saturday 4th September 2010

Muscular Dystrophy Ireland (MDI) in conjunction with Trim member, Niall Winters is hosting a Golf Classic in the South Meath Golf Club, Trim, Co Meath on Saturday 4th September 2010. MDI hopes that this event will be a tremendous success and will raise in the region of €5,000 towards MDI’s respite support services and medical research.

MDI is seeking help with this fundraising event and is offering individuals, shops, businesses, banks etc. three options to get involved. You can do so by:

1) Sponsoring a tee box at €50 per box, with your business / company name displayed.
2) Taking part as a team in the Golf Classic, at €160 per team.
3) Sponsoring a prize or making a donation of your choice.

Further information & to register contact:
Paul Harris: 086 813 5272
Michael O’Flaherty: 086 3535980
Amy Bramley: 086 8185352

Golf Classic Details

Straight Scramble 4 Ball
€160 per team
Time sheet available from 7.30am & the last tee off is at 3pm
Food included on the day.

Bag Pack at Marks & Spencer
Saturday & Sunday the 11th & 12th of September 2010
At Marks & Spencer’s, The Frascati Shopping Centre, Blackrock, Dublin

MDI is seeking volunteers for both days
Please contact Amy at 01 8721501 or email amy@mdi.ie

“Skydive 4 Charity Challenge” & support MDI

Ongoing!

Skydive 4 Charity gives you the opportunity to make a tandem skydive for your chosen charity.

Each Sponsorship Card ordered requires a non-refundable booking deposit of €20.00. This deposit is part of the minimum €600 fundraising target you are asked to reach in order to complete your Tandem Skydive.

For more information or to download an application form visit: www.skydive4charity.ie or contact: Amy on (01) 872 1501 or email: amy@mdi.ie
The Cork Mini Marathon
The 29th Evening Echo Women's Mini Marathon will be held on

Sunday 26th September 2010

MDI is seeking support again this year.

For more information visit:
www.corkminimarathon.com/ or contact
Amy Bramley on amy@mdi.ie or phone
(01) 8721501
Thank you.

National Ploughing Championships
Athy, Co Kildare
21st – 23rd September 2010

MDI will have a stand at this years event and we will be selling MDI merchandise and handing out information. We would appreciate if anyone would like to volunteer their time at the event and help man the MDI stand.

For further information please contact Amy at 01 8721501 or email amy@mdi.ie

Annual Benefit Greyhound Race Night

Newbridge Greyhound Stadium
Saturday 9th October at 7pm

All are welcome to attend or support in any way possible, MDI will be seeking support from the general public to sponsor a race or advertise in the racing card.

If you would like further information please contact Amy at 01 8721501

Appeal for Volunteers!
Anyone interested in assisting with fundraising?

MDI fundraising events are ongoing help is always required. If you can help, MDI would really welcome your support. For further information please contact Amy Bramley on 01 872 1501 or email amy@mdi.ie.
On Monday 24\textsuperscript{th} May 2010, I went on an MDI camp which was held in Kilcuan Lodge, Clarinbridge, Co. Galway. Those of us from Galway met up with other members, drivers and PA’s. There were members from Mayo, Galway, Limerick, Kerry, Dublin, Kildare and Antrim, so the country was well represented. There were 12 members in total.

On our first evening a few of us went for a walk in the beautiful surroundings of the lodge, it was lovely fine weather. It was very relaxed as we started to get to know each other. The next day we planned our week’s activities, which included shopping, cinema, bowling, “Trad on the Prom” (a show), an outing to the dog track, a table quiz, DVD’s and of course watching the Eurovision. All of these activities were optional.

We went bowling in City Limits Oranmore and it was very enjoyable. We went for dinner in the Salthill Hotel and stayed for a show called Trad on the Prom, a mixture of traditional music, dance, singing and brief stories of when the Irish emigrated to America. To sum up, it was about our culture. I thought it was really excellent, this from someone who wasn’t even going to go to the show! Traditional music wouldn’t really be my thing, but for anyone thinking of visiting Galway I would highly recommend going to it.

On Eurovision night we all paid €1 and picked a country at random, I picked Belgium. It was good fun and the person with the winning country and the country that came last won the money – unfortunately I had neither! That evening we had a table quiz which was fantastic fun. Congratulations to the winners Margaret and Kevin. After the quiz, we sat around the TV watching the end of the Eurovision and chatting. There were some evenings we were joined by Patricia from Galway. I decided not to go to the dog track, but a good time was had by all who did go. Thanks again to Marcus (PA from Kerry) who made me hot chocolate as he had the previous year too.

It was time to go home on Sunday, so many thanks to Darren for dropping me home. Thanks also to Kate, Steph and Aisling for driving us for the week and thanks to the staff who helped on the week. Most of all, thanks to all the members for your friendship and fun.

Eileen Gromley, MDI Member – Galway

My name is Sammy Brill I am 31 years old, I have a physical disability called Anterior Horn Cell Damage. This means that my muscles are extremely weak. I use an electric wheelchair to get around. In August 2008 my lung collapsed and I ended up in the I.C.U. in Portiuncula Hospital on a ventilator. I was very sick but slowly I got better. My muscles became weaker due to being on the ventilator. I had to get a tracheotomy and use a nippy machine (this is a machine that aids your breathing). I also had to get a PEG tube (this is a tube that goes into your tummy to feed you). I had to get this because when you have a tracheotomy it can sometimes affect your swallow.

When I got better I wanted to come out of hospital, however due to my needs I was told that funding was not available for twenty-four hour care. I was told that this had never been done before and I was asked “would I not be better off in a home?” This was very hard to hear and something I would not accept. In my eyes, I had the right to live a happy and fulfilling life. I fought and fought but still I was told there was no funding. I heard that Minister Mary Harney was visiting the hospital to open two new units. On the day of her visit I asked my doctor to bring me to meet her. She spoke to me and listened to my story. A few weeks later her personal assistant told me that things were sorted for me and I would be leaving the hospital on the 4\textsuperscript{th} May 2010. I was over the moon. CAREMARK (midlands) were appointed to provide my care. I find them very nice and kind. They said that they are there for me to provide my care and to make me as happy and my life as relaxed as they can. With groups like CAREMARK independent living is possible no matter what your needs.

Sammy Brill
Over the next few issues of this newsletter we have decided to include a feature on “a day in the life” of various staff members of Muscular Dystrophy Ireland. The idea behind these features is to inform members and the public of the role MDI staff play within the organisation and to capture a snapshot of a typical day in the life of a staff member from various sections within MDI.

By conducting such an exercise we hope that individuals (both members and professionals) will obtain a greater knowledge and understanding into:

- the workings of MDI;
- the services MDI provides;
- the importance of such services and
- the difference it makes.

To continue on in this series, MDI’s longest member of staff agreed to share her story.

**Introducing “A day in the life of…… Antoinette Roche”**

Many of you may have spoken to me on the telephone over the past 22 years (yes I did say 22 years!!). My name is Antoinette Roche and I started working with MDI in February 1988. Way back then when I attended my interview with Mr. Derek Farrell (the then Director of MDI) the only thing I knew about muscular dystrophy was what I had read in a dictionary which was quote: “wasting disease of the muscles”. I have since learned that the word “disease” is not politically correct and that many people may find this term offensive. Therefore, we at MDI would never promote or use such a term to describe muscular dystrophy – the term “condition” is much more appropriate.

I began working for MDI on what was then know as a “FAS Social Employment Scheme”, for 20 hours per week. I remember at the time being told that this scheme was only for one year and that it would be unlikely that I would be employed with MDI beyond this period. Not true! In the meantime, Derek Farrell had left MDI and the then Chairperson, Mrs. Judy Windle asked me at the end of my first 12 months if I would like to stay on working with MDI, and of course I said “yes”.

My career with MDI all started in a tiny office in Monkstown, Co Dublin and from there we moved to more temporary offices (a prefab) in Christchurch Place. While there we made it onto the TV (in 1989) as part of a campaign to secure a permanent office space. We were successful and then moved to Carmichael House (Brunswick Street) in 1990 before moving once again to Coleraine House, and then to North Brunswick Street where we are now based. We are now however planning our biggest permanent move to Chapelizod in the future (possibly January 2011). I must say that each office we have moved to over the years was bigger and better and its amazing how MDI has grown so much over the years! Even our current office, which is now too small, seemed big back in 2004 when we moved!

With regards to my in role, I began as receptionist and held this position until the summer of 2006 at which time my role was to change to administrator. I remember at the time feeling very put out about this but hindsight can be a great thing and my new role suits me very well and I now prefer it to my old position. The main part of my job entails database inputting (of timesheets for Family Support Workers, Youth/Respite Workers, Carers) and also helping with large mail outs such as the MDI newsletter and general office duties.

Hubert (who most of you know) is my mentor and from early on became my “computer tutor”. He started with MDI one year after me. I was completely computer illiterate (and some of my colleagues might say I still am!). But I like to think that what I lack in computer expertise I make up for in other areas of my job. The old golf ball typewriter (dinosaur as it now seems) was my best friend back in 1988. There have been many many staff that have come and gone over the years in MDI but my one constant companion has been Hubert. I hope that by my mentioning this for all to see that, he will know how much he means to me.

It’s been an interesting 22 years, ups and downs, but mostly ups! I hope I’ll have many more years here as I now consider my little desk in MDI to be my “home from home”.

Antoinette Roche
Administrator – MDI
The Carers Association’s Carers of the Year and Young Carer of the Year (under 18) Awards are based on a national nomination process, whereby the public are invited to nominate their chosen family carers. All entries will receive a commemorative certificate and four regional winners are chosen. The National Carers of the Year 2010 will be announced at a special ceremony later this year.

The awards nomination process for 2010 has already begun. Anyone can nominate a Carer they feel should be rewarded for their tireless dedication to a loved one, neighbour or friend. There is also a special category of awards – Young Carer of the Year. Young Carers are under 18 years of age who provide care to sick and/or disabled relatives in the home. Their work often goes unrecognised and their own social, health and educational needs are often neglected.

To nominate your family carer for the Carers of the Year Awards 2010, sponsored by Emergency Response, visit the Carers Association website at www.carersireland.com and click on: “Nominate a Family Carer Today”.

Please note the closing date for receipt of nominations is Friday, 10th September 2010.

There are an estimated 161,000 family carers in Ireland, providing over three million hours of care per week and saving the state EUR2.5 billion every year. According to the Census 2006, there are 5,500 young carers under 18 caring for relatives, a figure The Carers Association finds a huge underestimation in comparison to figures from the UK and Scotland.

The Carers Association
Invites Family Carers to join a one day stress management course in October 2010
For Family Carers
in Blanchardstown Village, Dublin
For an application form and more details please phone 01-8119555 or contact:
The Carers Association,
Marian House,
The Rise, Main Street,
Blanchardstown,
Dublin 15

Newsletter by email
Do you receive this newsletter by post? Would you consider receiving an email notification of when the next issue is available? By doing so, you would help to reduce our printing costs for this newsletter.

If you wish to receive notification of future issues via email, please email newsletter@mdi.ie. You will then be removed from our newsletter mailing list and no longer receive hard copies unless otherwise requested.

Remember, all previous issues of the MDI News Update can be downloaded from the MDI website at www.mdi.ie.

Help us reduce costs! Thank you!
New MDI Information Centre of Excellence

The Vision

It has been a dream of MDI members to develop its own resource, information and respite support facilities for many years. In 2009 MDI saw this dream become a reality when we purchased our first ever premises. This vision has been sought by members for many years and we at MDI are delighted to announce that we are now in a position to progress this vision to the next level. This is a very exciting development which will mark a new milestone in the history of MDI.

MDI’s new Information and Support Centre of Excellence for People with Neuromuscular Conditions (as it will be known) will be located in Chapelizod, Co Dublin, which is just five minutes drive from Heuston Station and two minutes off the N4. This location will make it easy to get to and there are also four local wheelchair accessible bus routes which pass outside the premises.

The Premises

The building itself requires extensive renovations to make it fully wheelchair accessible so full planning permission was sought for and approved in 2009. On 5th July 2010 work commenced on these renovations and the proposed completion date is mid January 2011.

This premises will act as MDI’s new Head Office and will cover all aspects of living with a neuromuscular condition, from point of diagnosis, to the need for information through to all support services that will be required. There will be a display area for aids and appliances and the use of specialized equipment e.g. hoist slings, power chairs, beds etc.

This facility will also be used to empower members through a training and development section incorporating a computer room, library and training room. A large boardroom will also be available for hosting meetings, AGMs etc. It will also encompass the administration of MDI services nationally which include Family Support Services, Youth Services, Adult Services, Respite Service, Training Service, Transport and Equipment Service, Information and Research Support.

The second floor of this building will consist of one self contained wheelchair accessible apartment which will be available to provide short term respite for MDI members. We are particularly excited about this aspect of the project as it will provide accommodation to MDI members and their families nationally who need to attend clinic or hospital appointments or to visit members in hospital, etc. This is a new development in the provision of MDI services which we are especially pleased about.

As far as we are aware, this centre will be the first of its kind in Ireland and we believe that this new facility will enhance the supports and services which MDI currently provides to members. It will also act as a one stop shop to meet all members’ needs (e.g. respite facilities, information, hands on trial of aids and appliances, etc).

We look forward to entering this new and exciting era in the growth and development of MDI, and with your support we can strive to ensure that this facility will indeed be a unique “Centre of Excellence”.

A progress report on the new premises with photos etc will be available on the MDI website (www.mdi.ie) in the coming weeks.