Editorial

Hi Folks,

It's newsletter time again. I feel like I've just completed the last issue – where does the time go? I hope you all had a nice summer. Holiday breaks, youth camps and the return leg of our Spanish exchange programme kept everyone busy here (see pages 5-7 for more).

Our "Research Update" column by Karen Jameison on page 2 explains about the different types of congenital muscular dystrophy and on page 3 you will find details on the Duchenne Parent Project annual conference in the U.K, which some of you may find interesting.

The MDI AGM takes place on Saturday 27th September (see page 4 for more). Also on page 4 are details of the MDI Family Day, on Sunday 5th October in The Heritage Hotel, Portlaoise. This will be an informal event, with lunch and entertainment and will give members and their families the opportunity to meet up with each other, We hope you can come.

With plenty of other articles throughout, I hope there will be something which you will find interesting.

Until next time, enjoy.  

Hubert McCormack
Editor

We are moving

MDI have secured new office accommodation in Dublin, as expansion is necessary with the increase in staff and services.

From 27th October our new address will be:

Muscular Dystrophy Ireland,
71/72 Red Cow Lane,
North Brunswick Street,
Dublin 7.

Telephone and Fax numbers will remain the same.

The new office location is less than five minutes walk from Coleraine House, situated half way down Brunswick Street (on the opposite side to Carmichael House – where our previous office was).

Members are welcome to visit during office hours.

Joanne Cleary (MDI Youth Worker, Galway) & Rachel Clarke, from Cork, pictured at an MDI Youth Camp in Galway from 19th – 27th July.
Research Update 7
Congenital Muscular Dystrophy

There are different types of congenital muscular dystrophy, so while some people have only muscle weakness, some might also have learning difficulties of varying degrees, and some might have epilepsy. The most severe type is called Fukuyama congenital muscular dystrophy, and this has been found almost exclusively in Japan. The term "congenital" means "from birth" and children with congenital MD are usually diagnosed shortly after birth or within the first six months. Sometimes it can take longer though. The severity varies greatly from person to person, and the condition can sometimes stay quite stable.

Congenital MD is often caused by a deficiency in a protein called merosin (also known as laminin-m), and this normally connects the muscle framework to supportive structures outside the muscle membrane. In about half of the people with "classical" congenital MD, the merosin M-chain (or laminin alpha 2 chain) is missing in the muscles. People with this diagnosis have merosin negative congenital MD. Most people who lack merosin have a genetic fault on chromosome 6.

Some people have what is known as merosin positive congenital MD. These people probably lack a protein related to merosin, but the gene abnormality has yet to be identified.

Scientists are looking toward gene therapy as a treatment or cure for congenital MD. So far, the use of an agrin minigene has been effective in reducing the severity of symptoms in a mouse model of merosin negative congenital MD. Agrin has the ability to bind to molecules that merosin usually associates with. Researchers led by Markus Ruegg at the University of Basel in Switzerland, introduced an agrin minigene into a mouse model using gene transfer technology, and there was a significant improvement in the muscle structure of the mice. The researchers hope that one day, people with this type of congenital MD could be treated with virally delivered miniagrin or a drug that boosts the body's natural production of agrin. These approaches could avoid potential immune reactions caused by giving the merosin protein to someone whose body has never seen it.

Muscular Dystrophy Association USA funded researcher, Stephen Kaufman, said that this study "adds to the potential for using complimentary genes to provide a remedy for the defective genes that cause muscular dystrophy" but added that much work needs to be done to develop such an approach.

Approaches other than gene therapy are also being tested. There is evidence that inflammation plays a role in merosin negative congenital MD. Prednisone and other corticosteroids (often prescribed in Duchenne MD) suppress inflammation by acting directly on blood-borne immune cells and by blocking complement - a set of proteins in the blood that stimulates the activity of immune cells. Anne Connolly and her colleagues at the Washington University School of Medicine tested the effects of prednisone and complement inhibition on mice with merosin negative congenital MD. Mice lacking the gene for C3, a complement protein, lived longer than those with normal C3. Treatment with prednisolone (a liquid form of prednisone), led to even greater increases in survival and strength. Again, this is encouraging research, but there is still work to be done. Further trials are necessary to see if this approach would be effective for children with congenital MD.

For further information, see the congenital muscular dystrophy pages on the American Muscular Dystrophy Association website, [www.mdausa.org](http://www.mdausa.org) or check the UK Muscular Dystrophy Campaign website, [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) (via information section, congenital muscular dystrophy factsheet, then link to annual condition specific review).

Karen Jameison
Information Officer, MDI
Duchenne Parent Project

Annual Conference
25th October 2003

The Duchenne Parent Project U.K. is holding a conference on Saturday 25th October 2003 at Imperial College London, Sherfield Building, South Kensington Campus, Exhibition Road, London SW7.

Top U.K. scientists will be speaking at the conference, including Prof. Kay Davies, Dr. Dominic Wells (who spoke at MDI's conference in September 2002), Prof. Terry Partridge, Marion Main (Senior Physiotherapist) and Michelle Eagle (Research Physiotherapist). They will discuss current treatments for Duchenne muscular dystrophy and the future for research.

Topics covered will include gene transfer, stem cell research, utrophin, steroids, night ventilation, cardiac monitoring and physiotherapy.

It will cost £20 sterling per person to attend this conference, and this includes lunch and dinner. Registration forms are available from the Parent Project [www.ppuk.org], tel: 0044 2920 190066.

Accommodation is available at special conference rates in:
Radisson Edwardian Vanderbilt Hotel (4 star): £80 single / £90 double.
Cranley Gardens Hotel (3 star): £60 single / £75 double.
These can be booked with Marie at m.ernsting@imperial.ac.uk or tel: 0044 207 5949533, quoting "Parent Project UK Conference".

A Life Worth Living


Jonathon was diagnosed with Duchenne muscular dystrophy at the age of 5, but is now 35 years old. Although he has used a wheelchair from age 10 and has been reliant on a ventilator for the last 13 years, he has led a full and varied life and is continuing to do so.

Jonathon has travelled extensively in the USA and Canada, and has flown on Concorde twice. He was an accomplished artist until he became too weak to hold a brush or pen, but he has adapted and gained new hobbies. He loves bird-watching, and can travel around different nature reserves with the aid of his portable ventilator. With adaptations, he uses a computer at home, and has found the internet useful for pursuing his interest in birds and for keeping in touch with friends.

Jonathon wrote the book to give doctors, carers, therapists and people with DMD and their families an insight into living with the condition. It includes chapters on ventilation, physiotherapy and the spinal fusion operation. He says "I also want to demonstrate that it is possible to overcome severe disability and lead a fulfilling life while at the same time adapting to the changing patterns the disability imposes".

If anyone is interested in purchasing this book, Karen in the MDI office has some order forms, or you can email Jonathon Colchester at jon@colchester.fsnet.co.uk. The book costs £9.99 sterling plus £1.40 postage and packing. All proceeds go to the Muscular Dystrophy Campaign, UK.
Invitation to Members

MDI Family Day

Sunday 5th October 2003

The Heritage Hotel, Portlaoise, Co. Laois.

2003 is the European Year for People with Disabilities and to mark this occasion MDI is holding a family day for members and their families, on Sunday 5th October 2003 in The Heritage Hotel, Portlaoise, starting at 1.00pm.

This will be an informal event, with lunch and entertainment for an afternoon, giving members and their families the opportunity to meet up with each other, socialise and celebrate the year.

If you are interested in coming along, please let your local Family Support Worker know, or contact the MDI office on 1800 245300 before 2nd October 2003

We look forward to seeing you then

Annual General Meeting

The Annual General Meeting of Muscular Dystrophy Ireland will take place on Saturday 27th September 2003 in Carmichael House, North Brunswick Street, Dublin 7.

Prior to the AGM, Prof. Kay Ohlendieck, from the National University of Ireland, Maynooth, will give a report on his first years' findings on the research project entitled: "Identification of Novel Therapeutic Targets in Dystrophic Muscle fibres", which is being funded by MDI.

The format for the day is as follows:

12.00pm Prof. Ohlendieck's presentation
1.00pm Lunch
2.30pm Annual General Meeting

We hope to see you there

Pictured at a recent reception in the Mansion House, Dublin, hosted by the Irish Youth Foundation (IYF) are Simon Jameson, Noeleen Fagan and Ciaran Purcell receiving a cheque for €15,000 from the IYF to produce a video for the MDI youth club
Irish / Spanish Muscular Dystrophy Associations Youth Exchange
(second leg)

In September 2002, a group of 10 members from Muscular Dystrophy Ireland, and their personal assistants, travelled to Madrid in the first stage of a youth exchange project. The second stage of this project took place from the 20th to 28th August 2003. A group of 9 members from ASEM, the Spanish Muscular Dystrophy Association, and their personal assistants, travelled to Ireland to explore the similarities and differences in culture between the two countries.

A film crew from Brussels, on behalf of the E.U. Commission, filmed the participants on the exchange to get the real views of young people living in Europe today. The resulting eight minute programme will be broadcast all over Europe.

In this, the European Year for People with Disabilities, the exchange was an opportunity to promote youth with a disability from two different European countries. Participants on the exchange were involved in a range of activities, including arts and cultural visits, music activities, and workshops on social exclusion topics.

Arts and Cultural Visits
Based in UCD, Dublin, the participants visited places of cultural and historic interest including the National Museum of Modern Art and the National Museum in Dublin. Trips to Glendalough in Co. Wicklow, the Festival of World Cultures in Dun Laoghaire and The Arlington Hotel in Dublin were also organised, where participants enjoyed traditional Irish music and Irish dancing exhibitions.
Workshops
Most mornings throughout the exchange, workshops were held and here participants compared what they have seen in Ireland with Spain and shared personal experiences and barriers in their lives. On Wednesday 27th August, the participants gave presentations on their findings from these workshops to a group of invited guests at 2:00pm in the O’Reilly Hall, UCD. These presentations focused on three main areas, Equality and Legislation, Social Equality and Gender Equality.

In total there were 19 members with the condition muscular dystrophy who participated in this project and a great time was had by all.

A special thank you to Leargas, who funded this project and to everyone else who gave their support.

Thanks To Everyone
By: Gustavo Adolfo Aguilar

For all those who have helped me, this gift I have reserved for you.

Thanks to your generosity, I have been able to put out the flames of adversity.

You always worry for me, trying to make me a little happier.

Every time that sickness takes hold of me, you do everything possible to come and visit me.

In you I have been able to find support social and sentimental, in you I have been able to find, the vaccination against loneliness.

You have made me understand that not everyone in this world moves out of self-interest and although some of you I will not see for a long time, do not worry. Because in the album of my memory you will remain.

Gustavo was one of the Spanish participants who wrote the above poem about the exchange before returning home to Spain.

Thank You
Table Quiz raises €1,200 for MDI

MDI would like to thank the Newbridge Town Football Club and Eamonn Nolan for raising €1,200.32 at a recent Table Quiz for the MDI Youth Exchange Programme between the Spanish Muscular Dystrophy Association and MDI.

The Irish leg of the exchange took place from 20th – 28th August 2003 and was a great success.
Hello everyone,

I hope you are all keeping well. My name is Eileen and I want to tell you about a trip to Mayo that I was on at the end of May with MDI. There were four of us from Galway (Caroline Moran, Joanne Cleary, Barbara Kelly, and Myself) two from Wexford (Cathy and Fiona Geraghty) one from Sligo (Fintan Flannery) one from Cork (David O’Mahony) and two from Donegal (Ann and Peadar Love). Caroline and Joanne from MDI were our drivers.

Before we set off for Mayo the Galway gang stopped at the Menlo Park Hotel to meet up with Fintan and David and then we had lunch. We had beautiful weather travelling. When we got there and checked in we were able to relax, some stayed in their rooms and watched tv. The name of the hotel was the Clew Bay and it was very nice. We took a walk in the evening after having been out for a meal. We took things easy that night because we were all tired.

The next day we set off for the Museum of Country Life in Turlough which showed Ireland as it was in the old days and how the kitchens looked. After that we went to see where and how the Foxford wool is made, there was a tour on how the Woollen Mills came to be, the struggles people went through and some information on Foxford itself. It was very interesting and enjoyable. That evening we went out to eat but didn’t stay up late because we had to travel the next day.

The following day shortly after breakfast we took a trip to Kylemore Abbey which was beautiful, and we went to the gardens which were beautiful. The weather was fabulous. Later we went on a boat up through Killary Harbour which was good fun and very enjoyable. We then had our evening meal and some drinks.

We did some shopping before going home the next day. We said our goodbyes and left with having made great friends for life and lovely memories.

By: Eileen Gormley, Galway

L-R: David O’Mahony, Caroline Moran, Fintan Flannery, Eileen Gormley (seated) Barbara Kelly, Cathy Geraghty and Fiona Geraghty, pictured on holiday in Mayo with MDI.
My Day At The Heineken European Rugby Final

Last June, MDI Member Neil Sheehan from Offaly, received two tickets from MDI to the Heineken European Rugby Final in Dublin. The following is an article Neil wrote (with a little help from Dad!) afterwards.

I awoke Daddy at 7.30am on the morning of the rugby game. We drove to Portlaoise where Daddy had to collect some parcels. We stopped at a service station for a breakfast roll outside Portlaoise.

We had some time to spare when we got to Dublin so we visited the Square shopping centre in Tallaght. Here we got a birthday present for my aunt Mary & a present for mammy & my brother Louis. I bought some cool stuff in the joke shop. For lunch we had a KFC before heading to the match.

As we arrived at the match fighter jets screamed over the stadium. The weather for the game was fine & we took our places in front of the loud Toulouse supporters. I enjoyed their singing in French, beating their drums, twirling their twisters & blowing their trumpets & horns.

The game started and Toulouse were playing the better. They scored a try towards the end of the half in front of us (and I was on TV for the replays of the try). Toulouse were 19-0 ahead at half time having played with the wind (Daddy explained).

Daddy queued at half time for a hot dog & this took almost all the half time break. At the start of the second half a man ran onto the pitch with no clothes on & he must have been freezing! The guards led him away and the game continued. Perpignon came back into the game and their supporters began to roar and make lots of noise (the roar from these guys was unbelievable).

It wasn't until the last few minutes that Toulouse got the score to secure the win and their fans erupted behind us. They sang and chanted until after the final whistle.

We watched to see the cup presentation and the Toulouse players came down near us to salute their fans.

As we headed back to the car I told Daddy what an enjoyable day I had and we started work on this report on the way home.

Neil Sheehan from Offaly
Age 7

South East Branch Sponsored Walk

The South East Branch of MDI are taking part in a sponsored walk on the 21st September at 12.00pm, at the Regional Sports Centre, Co Waterford.

All members of the Branch are welcome to attend. Your support is very much appreciated.
MDI would also like to thank Bernie Reilly and friends from Cavan (pictured above) who raised €2,093.00 for the MDI Holiday & Respite Service, which was presented to Siobhan Windle from MDI at a function on 31st August 2003 in the Meadow View Public House, Cavan.

Encouraging Voices is a book which explores the perspectives of young people from marginalised groups about their educational experiences and has involved their active participation in collaboration with researchers, teachers and adults with disabilities. A common theme, which runs through all the chapters is the desire to ensure that opportunities are provided for all learners, regardless of need, ability or background to participate fully in the education process. Disability, culture and social background continue to provide excuses for failure and to produce stereotyped beliefs about what pupils can achieve. The young people from marginalised groups desire a normality that involves access and achievement within the educational system and ambition for their success from teachers and policy makers. These young people want to contribute to a world where difference is accepted and valued as opposed to a ‘shadow world’ governed by charity and dependency.

The authors come from a wide range of disciplines and backgrounds. Some write from personal experience of disability or of being a member of a minority community in an educational institution. Others report on their experience as professionals who have attempted to support groups or individuals by providing an opportunity for them to express their own views or become more involved in their own education.

Encouraging Voices is priced at €20 and can be ordered from National Disability Authority, 25 Clyde Road, Dublin 4. Tel: (01) 6080400 Fax:(01) 6609935 Email: publications@nda.ie

SMA Contacts

MDI recently received the following email from Garry Toner from Armagh. Garry has asked us to include his email in our next newsletter.

"I am a 37 year old male electric wheelchair user with SMA. I would like to meet others around my own age to discuss issues regarding this particular disability. I live in the North of Ireland. I’m very proactive within a number of organisations within Armagh. Unfortunately I really don’t know anyone with the same disability as myself. I read your newsletter and find it very interesting. Maybe you could possibly give me some contact details?"

If you would like to contact Garry, his email address is: GarryToner@aol.com

Thank You

MDI News Update
Two monthly newsletter - Issue 13, September 2003
European Backing For Pioneer Disabled British Polar Explorer

A British man who later this year aims to be the first disabled person in the world to reach the North and South Poles has received official backing from the 2003 European Year of Disabled People.

Hertfordshire MEP Richard Howitt, who is President of the All-Party Disability Group of MEP’s in the European Parliament [campaigning for full civil rights for Europe’s 37 million disabled people], visited the home of Michael McGrath on Friday 18 July 2003 to hand over a European Year of Disabled People flag for him to plant at the South Pole [90° South] when he arrives.

Businessman Michael McGrath, who has Muscular Dystrophy, will write history in January 2004 when he becomes the first disabled person in the world to reach both North and South Poles. This will be the completion of the second phase of a two-year project called pole2pole, the inaugural event for The Muscle Help Foundation [MHF], which seeks to raise in excess of £1m for research into and relief from global muscle disorders including Muscular Dystrophy, a progressive muscle wasting condition.

Richard Howitt MEP says, “Michael's ambition to be the first disabled person to journey to both poles is an inspiration to us all. His expedition in a few months time to the South Pole will be a fitting climax to 2003 as European Year of Disabled People.

I look forward to seeing the photographs beamed back from Antarctica of Michael planting the EYDP flag at the Pole for disabled people, not only in the UK but all across Europe”.

"I also strongly appeal to the local business community to put their financial support behind Michael's project. His ambition and personal commitment sends the message that as employers they can do much more to identify the strengths of an individual and not judge disabled people on what they can't do, but rather on what they can do. As Michael's ambition to be the first disabled person to reach both Poles shows, it's about ability, not disability."

For further information -

- Official website: [www.musclehelp.org]
- MHF Campaign Headquarters: +44 1763 274658
- Michael McGrath mobile: [07958] 463434

The Butterfly

I describe you as a butterfly because like them you had so many magical ways, like their colours everyday you sparkled, your presence wonderful as it was, touched so many lives and even now you're gone, the butterfly will carry on.

I do believe you are a butterfly, every time I see one your wonderful presence is felt, I do believe you are a butterfly that heaven has sent.

I always told you you were beautiful, never believing a word I said, I do hope now you believe me, look what heaven has sent. You may not have been able to walk or go to some destinations, in your dreams, now you're a beautiful butterfly, you can go anywhere because God has given you wings!

By: Stephanie Buckley
In memory of her Aunt, Belinda Lacey, who was a member of MDI and died recently – R.I.P.
Took to the sky for MDI and raised over €4,000.00

Thanks to the following (pictured below) who "Took to sky for MDI" with the Falcons Parachute Team, Hacketstown, Carlow, on Saturday 6th September and raised over €4,000.00 for the MDI Cork & Dublin Youth Clubs.

From Cork: Tony O'Mahony, James Kelleher, Leonard Bolster, Danny Ring, David O'Driscoll, Colin Tasse, Gillian Ring, Mary-Rose Howell.

From Dublin: Sinead O'Brien, Noeleen Fagan.

All landed safely. Congrats on a great achievement and thanks again to everyone concerned.

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URL: http://www.parfit.ie/

Congratulations to MDI members

Jean Butterly from Dublin on her 30th birthday and to Dymphna Mooney from Donegal on her marriage to Emmet Whelan.
This page features a selection of Christmas cards available from the MDI office. The cards featured below are last year’s stock, and are sold in packs of 8 (one of each card, with envelopes. Size A5) for €5.00 a pack (plus 50c postage per pack). Verse inside reads: “With the Seasons Greetings and All Good Wishes for the New Year”

We also hope to have a new selection of cards available shortly.
To order any of these cards, contact the MDI Office.