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## Editorial

Hello again,

Welcome to the September issue of the *MDI Newsletter*. If you're thinking "wow, it doesn't seem like two months since the last issue", well you're right, because it's not! This issue is about two weeks ahead of schedule as I'm off on holidays and wanted to get it out to you before I left. Because it's a little earlier, it's a few less pages, but as they say "some news is better than no news!"

Karen's Research Page in this issue looks at new developments in gene therapy where dystrophin protein delivered to all voluntary muscles with a single intravenous injection in mice with Duchenne MD show encouraging results (see page 2 for more).

*"Making sense of Duchenne Muscular Dystrophy"* is the title of a conference, which is being organised by Parent Project UK & Muscular Dystrophy Campaign in September. This conference will offer parents, family members, carers, professionals working with people with Duchenne muscular dystrophy (DMD) and fellow researchers an opportunity to find out more about DMD research in the UK (more on page 3).

If you are the sporting type, check out page 3, where DCU are offering students with disabilities the opportunity to avail of a sport scholarship. Also, on the topic of sport, if you're into fishing you'll be interested in an article on page 2, where a Munster angling club has recently acquired the first ever wheelchair accessible fishing boat on an Irish river.

You may have already heard that the Annual General Meeting of Muscular Dystrophy Ireland will take place on Saturday 9<sup>th</sup> October 2004 in our Head Office, on 71/72 North Brunswick Street. More details on back page.

I know it's only September, and I apologise in advance for mentioning Christmas, but just to let you know that we have new MDI Christmas cards this year, which are now available (details on page 7).

There are also some other articles from members around the country included within, so hopefully there is something of interest for all.

Until next time, take care.

**Hubert McCormack**  
*Editor*



### Sister Soccer Stars!

*Soccer stars of the future, sisters Serena and Maureen Brennan, MDI members from Westmeath, being interviewed by a TV3 film crew at a recent MDI Power Soccer Tournament.*

## Research News

### New Gene Therapy Development

On 25<sup>th</sup> July 2004, Jeffery Chamberlain and colleagues from the Departments of Neurology, Biochemistry and Medicine at the University of Washington published new research in the online edition of the journal Nature Medicine (it will feature in the August print edition). The news also featured in the Irish Independent and UK Independent newspapers on 26<sup>th</sup> July.

The breakthrough in this research is that they managed to deliver the gene for the dystrophin protein to all voluntary muscles with a single intravenous injection in mice with Duchenne muscular dystrophy. Achieving widespread delivery of the gene had previously been a problem.

Just one injection led to the gene being inserted into all affected muscles, including the heart, the muscles used during breathing and the limb muscles. The mice showed an improvement of their dystrophy.

On the American Muscular Dystrophy Association website, Prof. Chamberlain is quoted as saying "We now have obtained a proof of principle that it is possible to deliver new genes body-wide to all the muscles of an adult animal. The immediate goal is to find out if we can extend this work to people".

Research will take place to further test the technique to determine if it can be applied to humans, and to test the long term effects.

I'll keep you updated on the progress of the research.

**Karen Jameison**  
Information Officer – MDI

## Muscular Dystrophy Campaign Relaunches Website

The Muscular Dystrophy Campaign in the UK has relaunched its website and it now contains more information than ever.

As well as news and research updates, there are message boards and publications available to download. Publications available include booklets aimed at children and teenagers with muscular dystrophy, siblings, children going to school with a person who has muscular dystrophy and education guidelines for primary and secondary schools.

Check [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) for more information.



A Munster angling club was recently congratulated for its initiative in providing the first ever wheelchair accessible fishing boat on an Irish river when Minister for state Mr. John Browne, launched the Mark II Wheely Boat on the river Blackwater.

The initiative by the Cappoquin Salmon & Trout Anglers Association (CSTAA) is the first such project on an Irish river and will allow disabled anglers to fish a four mile stretch of the Blackwater where the club has fishing rights.

CSTAA honorary secretary Mr. Jeremy Nicholson revealed that the acquisition of the €35,000 boat – which can accommodate two anglers using wheelchairs. For more details e-mail: [jeremy@fishcappoquin.com](mailto:jeremy@fishcappoquin.com)

## Making Sense of Duchenne Muscular Dystrophy



**Muscular  
& Dystrophy  
Campaign**

### Parent Project UK & Muscular Dystrophy Campaign Conference

**25<sup>th</sup> and 26<sup>th</sup> September 2004  
Imperial College, South Kensington  
Campus, London**

This conference will offer parents, family members, carers, professionals working with people with Duchenne muscular dystrophy (DMD) and fellow researchers an opportunity to find out more about DMD research in the UK.

There will be talks on new developments in gene therapy and research, and management of the condition.

#### **Speakers include:**

#### **Leading Scientists in the Field of DMD Research:**

- **Prof. Kay Davies**, University of Oxford
- **Prof. Terry Partridge**, Imperial College London
- **Prof. George Dickson**, Royal Holloway London
- **Dr. Judith van Deutekom**, Leiden University, Netherlands
- **Dr. Steve Wilton**, Perth, Australia
- **Dr. Dominic Wells**, Imperial College London

#### **UK's Leading Clinical Consultants in DMD:**

- **Prof. Francesco Muntoni**, Hammersmith Hospital London
- **Prof. Kate Bushby**, University of Newcastle

#### **Senior Clinicians and Therapists Advising on the Management of DMD:**

- **Dr. Adnan Manzur**, Imperial College London
- **Dr. John Bourke**, University of Newcastle
- **Dr. Anita Simonds**, Royal Brompton Hospital London
- **Marion Main**, Senior Physiotherapist, Hammersmith Hospital London
- **Dr. Michelle Eagle**, Research Physiotherapist, University of Newcastle

The cost per person is £25, (approx €37.50) and this includes buffet lunch and evening meal.

Details on the conference are available from the Parent Project UK:

Website – [www.ppek.org](http://www.ppek.org)

Email – [info@ppek.org](mailto:info@ppek.org)

Telephone – 0044 208 281 4333

### **Dublin City University Sport Scholarship for Students with Disabilities**

Brenda Hopkins, Sports Development Officer at DCU (not to be confused with MDI's Brenda Hopkins – Youth / Respite Worker in the North East) is responsible for adapted physical activity in the university. DCU offers a limited number of Sport Scholarship Awards, to cover training, travelling and coaching expenses.

For the first year, the scholarships are being made available to students with disabilities. Brenda says, "By providing students with disabilities the opportunity to avail of the sport scholarship, it gives them the chance to focus on their studies, yet giving them the opportunity to further their sporting career."

Scholarships are only open to students who have secured a place at DCU and recipients of the award must compete within the appropriate sports club.

For more information contact Brenda Hopkins at the DCU sports complex on 01 7005810 or email [Brenda.Hopkins@dcu.ie](mailto:Brenda.Hopkins@dcu.ie)

## MDI YOUTH PAGE

### News from Cork/Kerry

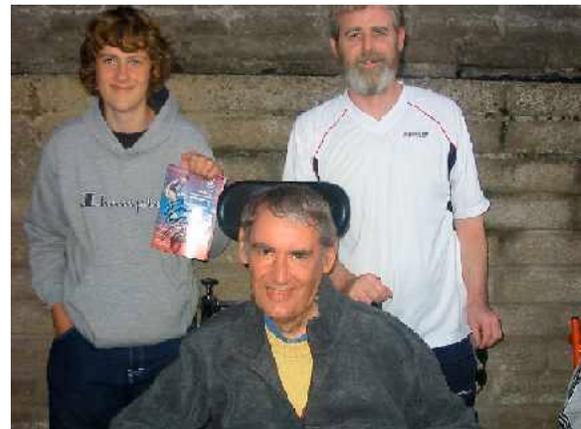
#### Roy's the Boy, for Cork MDI

Irish soccer legend Roy Keane was star attraction when a Manchester United X1 took on Cobh Ramblers at the Turners Cross ground, Cork on Saturday 17<sup>th</sup> July, in a benefit match for the Eircom League side.

A bumper crowd of 7,500 helped Roy to swell the coffers of the little club which started Ireland's top footballer on the road to success with Nottingham Forrest before moving on to Old Trafford.

Also up for the match was a party of 9 Cork MDI members and helpers in the capable hands of Mary-Rose, with the fabulous support of local Gardai and stewards who ensured hassle free parking and a prime viewing position on the night.

An entertaining game ended with United 2-1 winners and the final whistle saw Roy engulfed by hundreds of fans eager to obtain the famous Cork-man's autograph.



Pictured at the Manchester United Reserves v Cobh Ramblers match is MDI member, Chris O'Brien from Carrigaline (Centre), with his son Sean (left) and their driver Jim O'Donovan.

However, to the delight of our party, Roy battled through the crowd straight to the section reserved for disabled spectators, where he ensured our match programmes were top priority for the prized signature. Mary-Rose had also hoped for his telephone number but managed to hide her disappointment very well!!

Thanks to the Cork branch of MDI for a fabulous evening, a memorable occasion and an autograph to treasure.

**Chris O'Brien**  
MDI - Cork



### MDI Gota Fota!!

FOTA Wildlife Park in Cork is not like an ordinary zoo. Wherever possible animals thrive in a free-range environment, which allows them to roam free, and mix with other species and with us human visitors!

Visitors to Fota on Friday 18<sup>th</sup> June 2004, included members from the Cork Branch of MDI (pictured left) who also got the opportunity to mix with each other, roam freely and have fun on a family day out!!!



**Another Fota Photo!**

Ed O'Connell (centre) pictured with his cousin Gary, brother Shane and MDI Cork volunteer Una, at the FOTA Wildlife Park on 18<sup>th</sup> June 2004

## One Happy Camper!

*On 10<sup>th</sup> July, MDI member Keith McAuliffe (age 12) from Cork headed off to France on a camping holiday with his family. Upon his return, Keith sent in the following article:*

On 10<sup>th</sup> July my family and I went to France on our holidays. We borrowed the MDI bus, which Daddy drove and we had lots of space in it. We stayed on a campsite belonging to Canvas Holidays. Our campsite, called Sequoia Park in Marennes, was about 400 miles from Roscoff.

Our tent was very large and there was a bed for everyone and they were all off the ground, which was great. Also in the tent was a fridge, a cooker and a grill. There was also a barbecue outside. I could also charge my wheelchair in the tent.

Every morning I went to the "Hoopie Club" with my sisters. There was lots to do there, including treasure hunts, pirate games and T-shirt painting. There was also a very big wheelchair accessible toilet which had a shower and wash hand basin in it.

There were three swimming pools in the campsite and there was one step down to the pool area, therefore you would need to use a manual wheelchair. There were also lovely beaches near the campsite. One day we went to the Zoo in La Palmyre. While we were there, there was a sea lion show, which was great. We got drenched when the sea lion flipped over in the water in front of us.



MDI member, Keith McAuliffe (12) from Cork pictured on holidays in France with his two sisters, Sharon and Aisha, and "Canvas Holiday Friends".

Every night there was a disco or a show which was also great fun. I had a great holiday and would definitely go back again.

**Keith McAuliffe**



MDI Member David Stack, from Tralee, Co. Kerry pictured on a Cork/Kerry Youth Group Fishing Trip on 19<sup>th</sup> June last.

## Members of the North East Branch Visit Dublin Zoo



Pictured at the "Wishing Chair" in Dublin Zoo on 22<sup>nd</sup> July is: Karen Leonard (MDI Youth Worker), with MDI members Adrian Lambe, Ciaran O'Reilly, Shane Lambe and Fintan O'Reilly. Don't ask me what they wished for, but on all accounts a great day was had by all!!

## HAPPY 21<sup>st</sup> BIRTHDAY



Congratulations to MDI member Andrew Nolan from Newbridge, Co. Kildare who received the "Key of the Door" on Saturday 21<sup>st</sup> August when he celebrated his 21<sup>st</sup> birthday.

The celebrations for Andrew's party began at 9.00pm on Saturday 21<sup>st</sup> August in the Newbridge Town Clubhouse and I believe went on until the early hours of Monday morning (yes, Monday, not Sunday – in case you think this is a typo!!!) when they came to a halt at the Bush Pub in Ballysax. Oh, to be 21 again!!!



## Congratulations To Eamon Nolan

Congratulations to MDI Member Eamon Nolan from Newbridge, Co. Kildare who was recently awarded a bronze medal from **O<sub>2</sub> Ireland** for his fundraising endeavours and activities over the last 10 years. Eamon, whose son Andrew has Duchenne muscular dystrophy, has raised over €20,000 for charity in the last 10 years (half of which was for MDI). By accepting this award, Eamon will receive a cheque from **O<sub>2</sub> Ireland** for €500, which will also be donated to MDI.

We at MDI would like to thank **O<sub>2</sub> Ireland** for acknowledging Eamon's tireless fundraising endeavours and in particular we would like to thank the man himself, Eamon for his continued support. Congratulations Eamon and well done!

## Wheelchair Accessible Van For Sale

**Nissan Cargo, 2.3D.**  
**Year - 2001**  
**Mileage - 18000**  
**Colour - Metallic Green**  
**Seats: 2 in front & 2 in Back**  
**Rear Hydraulic Ramp**  
**Tinted Windows**  
**3 Restraints - 1 Front & 2 Back**  
**1 Chest/Seat Restraint**  
**Asking Price Approx - 10k+**

**Contact:**  
**Eamon @ 086 6005000**

## Muscular Dystrophy Ireland 2004 Christmas Card Order Form



Please send me (state how many)  packs of MDI Christmas cards.  
Each pack contains 6 X 2 assorted cards (as above)  
Packs cost €7.00 each plus 50c extra per pack (post & packaging).

*(Please use BLOCK CAPITALS)*

Name

Address

Tel:  E-mail:

I enclose €  payment for same

Payment should be made by cheque or money order and made payable to:

### **Muscular Dystrophy Ireland**

This order form should be returned along with your payment to:

**Steven Valentine**

**Muscular Dystrophy Ireland**

**71-72 North Brunswick Street**

**Dublin 7**

**Tel: (01) 872 1501 Fax: (01) 872 4482**

**E-mail: [steven@mdi.ie](mailto:steven@mdi.ie)**

Orders received after 30<sup>th</sup> November cannot be guaranteed.  
Please allow 7 days for delivery.

**A date for your diary!**



## Annual General Meeting

**- Saturday 9<sup>th</sup> October 2004 -**

The Annual General Meeting of Muscular Dystrophy Ireland will take place on Saturday 9<sup>th</sup> October 2004 at 2.30pm in the our Head Office,  
71/72 North Brunswick Street,  
Dublin 7.

Prior to the AGM, (at 12.00pm),  
Prof. Kay Ohlendieck, National University of Ireland, Maynooth,  
will present a report on the research project entitled:  
*"Identification of novel therapeutic targets in dystrophic muscle fibres"*,  
which is being funded by MDI.

**RSVP: (01) 8721501 before 27<sup>th</sup> September 2004**

## All Welcome

**Please Note:**

**Only paid up members of MDI are eligible to vote at the AGM**

We hope to see you there.