

Muscular Dystrophy Ireland 71/72 North Brunswick Street, Dublin 7.
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Editorial

Hello again,

Here we go again. July here already and school summer holidays well under way. Here at MDI, the holidays have got off to a great start, with breaks for members in Westport and Fermanagh (see pages 5 & 6 for more). And further breaks are planned for August.

Karen's Research News in this issue (page 2) reports on a consortium of scientists in the UK who were awarded funding of £1.6 million sterling for research into muscular dystrophy.

There is also a report on the All Ireland Symposium on Neuromuscular Conditions for Health Care Professionals, which MDI hosted in conjunction with our UK counterparts (MDC) in 9th June 2004 (see page 3).

I don't normally include articles that are too dated, as I try to keep this newsletter current. However, I have made an exception on this occasion and included an article from 10 year old Rory O'Donoghue from Kerry, about his trip to Chelsea with MDI last April (page 4).

Since the last issue, MDI have appointed two new members of staff. Aileen O'Mahony, Administration Co-ordinator and Karen Leonard, Youth/Respite Worker. Both Aileen & Karen introduce themselves on page 8.



Ciaran Purcell from Dublin (with instructors) getting ready to "be driven up the wall", while on camp in Fermanagh.

For your information, we have also included a timetable that gives contact details and the working days for MDI Family Support Workers and Youth Workers, which I'm sure you'll find useful.

I hope you enjoy this issue of our newsletter and remember to get those articles, photos etc. in to me before 20th August next for inclusion in our next issue.

Until then, take care.

Hubert McCormack
Editor



Group shot of the Ladies who ran in the Women's Mini-marathon for MDI in June, pictured with MDI's Fundraising Officer, Steven Valentine. (How come he gets all the nice jobs!!!!!!)

Research News

Funding Granted to UK Consortium

On 22nd March 2004, the UK Government revealed that a consortium of scientists had been awarded funding of £1.6 million to investigate a technique known as exon skipping. The news of this funding comes after campaigning by the Muscular Dystrophy Campaign, Parent Project UK and the Duchenne Family Support Group, with support from the All Party Parliamentary Group chaired by Kevin Brennan MP.

Professor Francesco Muntoni, the Principal Investigator for this project, from Imperial College London said *"Our consortium is delighted with the news of funding for this research leading to a clinical safety trial. Although this is only the first step towards developing an effective treatment for this condition, the consortium has the necessary expertise not only to test the safety of this approach, but also to try and improve its efficiency so that its impact could be even more significant in the future"*.

The project is coordinated by Jenny Versnal, Head of Research at the Muscular Dystrophy Campaign and involves a group of UK scientists and clinicians:

- Professor Francesco Muntoni, Professor of Paediatric Neurology
- Professor Kate Bushby, Professor of Neuromuscular Genetics
- Professor Terry Partridge, Professor and Group Head MRC CSC
- Dr Qi Lu, MRC Research Staff
- Dr Dominic Wells, Reader in Transgenic Biology
- Professor George Dickson, Professor of Cell Molecular Biology
- Dr Ian Graham, Senior Research Fellow
- Dr Matthew Wood, Lecturer In Human Anatomy & Genetics

Exon skipping is a technique used to modify the way in which genetic information is read, for therapeutic effect. A "molecular patch" (antisense oligonucleotides – short stretches of DNA/RNA that bind to genetic material and change the splicing pattern) would be injected directly into the muscles. Laboratory studies have shown that this patch can modify the faulty genetic code in Duchenne muscular dystrophy, leading to the production of dystrophin. This would not cure DMD, but would reduce the severity and make it more like the milder Becker muscular dystrophy. If

the technique leads to an effective treatment for DMD, it is worth noting that the effects of the patches are not permanent so the treatment would need to be repeated. Further funding will therefore be required to find more efficient methods of targeting all affected muscles. Also, if effective, the treatment would be of benefit to around 60% of boys with DMD, as the condition can be caused by a variety of different genetic errors on the dystrophin gene which have the same results. As the Muscular Dystrophy Campaign reminds, this is not the only hope for a treatment for DMD, there are other options being explored that could be useful for those where this technique is not an option.

It is thought that if this technique eventually leads to a therapy for DMD, the earlier a boy receives the treatment the more impact it would have on quality of life. It is unlikely though that if much of the muscle had already wasted that the treatment would be able to restore function or strength.

The aims of the project are:

- To optimise the construction of the patches to increase their efficiency and prevent them from being broken down too quickly once in the body
- To explore methods of delivering them to all affected muscles
- Ultimately to test their safety in humans.

It is estimated that it could be approximately four years before safety trials in humans can begin. People participating in this initial safety trial are expected to have no therapeutic benefit as it would involve delivering patches by injection into a small muscle to see if the technique is safe. If it was found to be safe, there would be a number of years of further clinical testing and it is difficult to estimate how long this could take. A clearer image may develop as the initial research progresses.

There are other groups in Europe, USA and Australia working in similar areas so the consortium will be in close contact with them.

Eventually, if a therapy is developed it is thought that the technique will be adapted to apply to other conditions, such as spinal muscular atrophy and myotonic dystrophy. To reach this stage however, there is a lot of work to be done and further funding will be necessary.

The information from this article is available on the Muscular Dystrophy Campaign website: www.muscular-dystrophy.org. In the "Latest News" section you will find an article called "Consortium Bid – Question and Answer Briefing Sheet".

Karen Jameison
Information Officer – MDI

All Ireland Symposium on Neuromuscular Conditions for Health Care Professionals

Muscular Dystrophy Campaign



On Wednesday 9th June 2004 MDI in association with the MDC (the organisation in the UK that provides support and information for people with muscular dystrophy) held a conference to raise awareness of muscular dystrophy and the needs of people with the condition, among health care professionals. A range of professionals attended, mainly occupational therapists and physiotherapists but also some social workers, psychologists and community care doctors.

The conference was officially opened by Joe Mooney and then put in the capable hands of John Dolan, CEO of the Disability Federation of Ireland, who was chairperson for the day. Karen Jameison gave an introduction to MDI and the services that we provide, and Ruth Geall, MDC Director of Research and Care did the same for the UK organisation.



Pictured L-R are: Siobhan Macauley, John Dolan, Sue Manning, Ruth Geall and Andrew Green at the All Ireland Symposium in June

The morning session proved to be very informative, with talks by Siobhan Macauley, Clinical Specialist Physiotherapist at Belfast City Hospital, Sue Manning, MDC Occupational Therapist and Family Care Officer, and Professor Andrew Green, Director of the National Centre for Medical Genetics in Dublin.

After a break for lunch the afternoon continued with presentations by Dr. Orla Hardiman, Consultant Neurologist at Beaumont Hospital Dublin, Jenny Versnal, MDC Head of Research, Professor Kay Ohlendieck who spoke about the MDI funded research project and MDI's own Hubert McCormack who talked about his experiences.



Jenny Versnal

There was also an opportunity to view equipment at display stands set up by Enable Supplies, Anti Slip Ireland, Beechfield Healthcare and Plantronics.

The day proved to be very successful and hopefully the health care professionals who attended left with a greater awareness of the different types of muscular dystrophy, the needs of different individuals and the services that are available for people who have the condition and their families.

Thanks must go to all the speakers who gave such excellent presentations, John Dolan who expertly chaired the conference and the Muscular Dystrophy Campaign for assisting with speakers and planning the event.

MDI would also like to thank the North Western Health Board, North Eastern Health Board and Mid Western Health Board for contributing funding towards the cost of this event, and Irish Life Assurance PLC, Tyco Healthcare and Smurfit Capital who also gave small donations. Without this funding MDI would not have been able to run this event.



MDI staff Sinead, Karen, Noeleen & Hubert pictured at the symposium.

My Blue Heaven by Rory O'Donoghue

Last April, a group from MDI travelled to Stamford Bridge in London to see Chelsea play Everton. In the previous issue of our newsletter, there were photos of this trip. We received the following article too late for inclusion in that issue, so here it is. Normally I would not print dated articles, however I thought this one, written by 10 year old MDI member Rory O'Donoghue from Kerry was great!!



Rory O'Donoghue from Kerry, pictured at his "Blue Heaven"

The start of my dream began in Kerry on Thursday 15th April 2004, I was going to see my beloved CHELSEA!! Of course my family, i.e my brother James, father Jimmy and Uncle John - all non Chelsea supporters) would have to endure the journey with me, how painful for them, he he!!!!

We met everybody in Bewley's Hotel, Newlands Cross, Dublin that evening and got acquainted.

Next morning Friday 16th, we left the Hotel, boarded the Boat for Holyhead and arrived at 12.30pm. After a beautiful mountainous journey through Wales, we arrived at Jurys

Inn, Chelsea. We had dinner with the group, whose names were, if memory serves me right, Séan, Séan 2, Séan 3 (old), Kevin, Senan, Noeleen, James, James 2, Brenda, Joe, Ashling, Noel (driver) and Alan (driver). I hope I remembered everyone. I was so excited I could not wait until the Match and went straight to bed straight after dinner.

Saturday arrived!!!

I'm at the home of **CHELSEA FOOTBALL!!! WOW!!!!!!** I had a field day at the Megastore, spent all my money, but I knew I'd have James as a back up, he being an Arsenal fan. Despite the match being a draw it was great just being at Stamford Bridge!

That night I felt my Kingdom luck would bring me a win at the cards. But the Kingdom luck favoured James. A great end to a great day!

Next homeward bound, feeling sad but happy, we departed my beloved Chelsea for my beautiful Kerry. Many thanks to all the wonderful people we met including Ashling my camera assistant, Noeleen the producer and Daddy the costume designer.

Thanks to all at M.D.I from Rory, James, Jimmy, John

Rory O'Donoghue , Director!



Glen Devoy from Dublin with his Dad Parkey, at Old Trafford in Manchester, following a Man United v Liverpool match on 24th April last.

MDI Adult Mid-Week Break *Westport – May 2004*

Hi there folks, Eileen here to tell you about the Adult Mid Week Break to Westport in Co. Mayo which took place from the 25th – 28th of May 2004.

There were seven of us on the trip namely; Patricia Hannon (Galway) David O'Mahony (Cork) Fiona & Kathy Geraghty (Wexford) Eileen Gormley (Galway) Joanne Cleary (MDI Youth Worker) & Fintan Flannery (MDI Family Support Worker).



"MDI News Update" Western Correspondent, Eileen Gormley, taking time out for coffee (at least, it looks like coffee!!!) at the Adult break in Westport.

We went to Westport and stayed at the Clew Bay Hotel. Myself, Patricia, David and Joanne met up with Fintan when we arrived and a little later, Fiona and Kathy arrived. We checked into our rooms and that evening we went out for a nice meal. It was great to catch up, and we had good craic, and of course we had to wash the meal down which is exactly what we did afterwards. We did not stay out too late, as we were all tired from the travelling.

We came down for breakfast the following morning refreshed, after having a good nights sleep. After breakfast we (Patricia, myself and Joanne) went shopping and then met up with the others. It was then off to Achill Island for the afternoon. We saw "You're A Star" finalist James Kilbane's house and lots and lots and lots of rocks and sheep!!!

When we got back oh boy, were we hungry? And thirsty too!! So we had another lovely meal, and again we quenched our thirst afterwards, but returned to the hotel at a respectable hour.

After breakfast the following morning we relaxed for a while before heading off to Castlebar for the afternoon for some shopping, lunch and some fun.

Later on that evening Joe Mooney and his wife, Aisling arrived and we all went out for a meal and then back to the Clew Bay Hotel where there was music. And yes folks!! I sang a song "What A Wonderful World". We had great craic.

The following morning we all got ready to leave and yeah!! I was sad because we had great fun. I can't believe how fast the time went, but sure we really had a nice relaxing time. Hope to see you all again soon.

***Eileen Gormley
Western Correspondent
MDI News Update!***

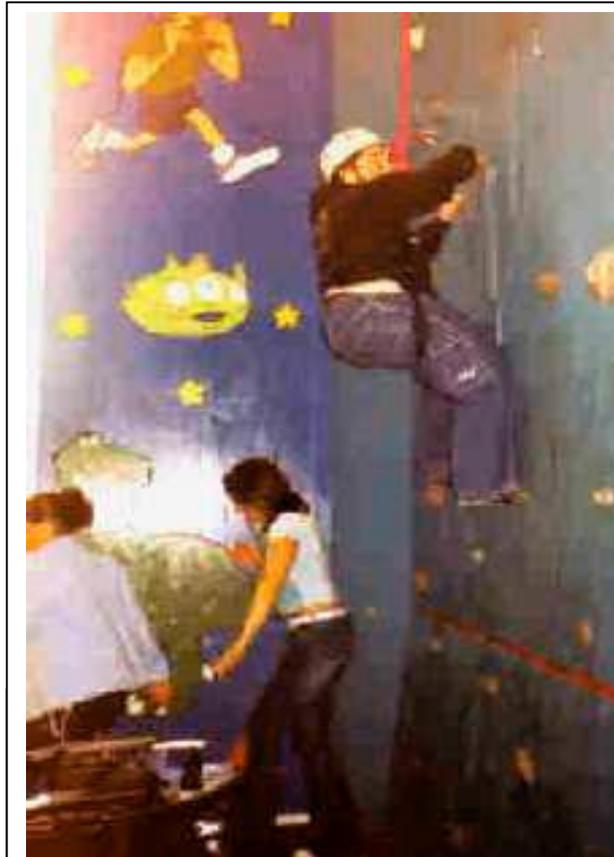
A late photo - last April!!!



"Girl Power!" L-R: Maureen & Serena Brenman, (Westmeath); Aisling McElligott, (Offaly); Leona Cuddy, (Laois) and Eimear McElligott, (Offaly) pictured at a recent MDI Branch outing to Disney On Ice.

Youth Camp in Fermanagh 29th June – 2nd July 2004

Thirteen young members went on the camp to Fermanagh on the 29th of June. We went to the Share Village where everyone had a fantastic time. The weather was not too kind to us but that did not seem to dampen our spirits. There was a great variety of activities organised on the camp including pottery, mosaics, archery, kite making and mod rock. There was also a chance for some rock climbing which Ciaran Purcell did twice and he thoroughly enjoyed it.



On the camp the members were able to have some free time to themselves, so lots chose to play power soccer and others had a Playstation tournament. The Playstation had been hooked up to a big screen in the sports hall, which went down very well with everyone.

Some of the members took full advantage of the swimming pool in the centre especially Des Mooney who I think beat everyone he took on in the swimming races.

On one of the days we went on a cruise of Lough Erne and the staff cooked a lovely barbecue. On the way back to the centre everyone was very sleepy after all the delicious food that had been eaten.

On the last day everyone went to Enniskillen to do some shopping, where people bought presents for their families and some presents for themselves as well! That night we had a disco where Noeleen was presented with a cake to wish her good luck in her new job and in the future.

By Friday morning everyone was looking forward to heading off home to see their families and to show them all the things they had made while on the camp.

I think we can safely say the camp was a big success and we look forward to the next one in August.

Karen Leonard
Youth/Respite Worker

Left Photo:

Noeleen & Sinead too scared to watch as dare devil, Ciaran Purcell is hoisted up the climbing wall in Fermanagh.

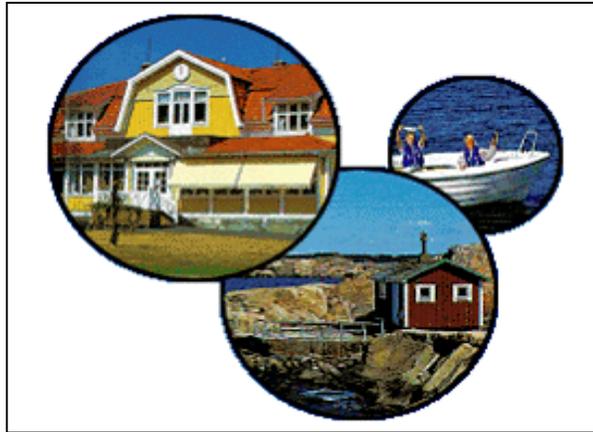
Below (left & right):

Members & Staff participating in Arts & Crafts workshops while on camp in Fermanagh.



Agrenska

Knowledge Makes Us Powerful is the motto of Agrenska, near Gothenburg in Sweden. It is a place providing programmes for children and young people with disabilities, their families and professionals. The aim is to help them to cope with everyday life, making it as independent and equal as possible.



At the European Organisation for Rare Diseases awareness conference in Cork on 26th June, Anders Olauson spoke of how successful Agrenska has been. A child's disability affects the whole family, so Agrenska offers programmes for everyone, including parents and siblings.

Family programmes are a week long, and are an opportunity for families to meet others who have children with the same diagnosis to spend time together and share experiences. Parents attend talks and discussions on medical and psychosocial topics, while other activities are organised for young people with the condition and siblings.

There is also a respite service at the weekends and during school holidays. Summer camps are organised and children can go for one or two weeks or even just during the day, going home at night. Activities such as swimming, boat trips and barbecues are organised, encouraging young people to make friends and become more confident. Nurses are on hand for children with any conditions requiring medical attention, such as diabetes or epilepsy.

The Agrenska Academy arranges courses and conferences for professionals, including teachers, social workers and healthcare professionals.

Most people attending Agrenska come from the local Gothenburg area but some travel from further parts of Sweden.

Anders Olauson says that the programme makes families feel empowered, parents get the knowledge to take better care of their own lives, children meet others in similar situations, siblings share their experiences with others who understand – they are faced with possibilities rather than problems.

There is also a financial benefit. The cost of healthcare for families not taking part in a programme such as this is SEK 35,200 (€3834) per year, compared to SEK 13,300 (€1449) for those who do take part. Olauson believes that this is because the informed family know when they should seek medical care for their child, where they should go and who to ask for, and they also know when they can manage themselves and do not need to go to hospital.

Increasing information and awareness, including the whole family and promoting independent living are aims that apply to other centres and organisations throughout Europe.

To find out more about the Agrenska programmes, see www.agrenska.se.

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New Staff

Since the last issue, MDI have appointed two new members of staff. Aileen O'Mahony took up the newly created position of Administration Co-ordinator in June. Also in June we appointed a new Youth/Respite Worker, Karen Leonard for the Eastern region. Karen will replace Noeleen Fagan, (a hard act to follow!!), who went to work for Foroige. MDI would like to thank Noeleen for all her hard work and wish her well with her future career. We would also like to welcome Aileen & Karen aboard and wish them well in their respective posts. Below, Aileen & Karen both introduce themselves:

Aileen O' Mahony Administration Co-ordinator

Hello Members,

My name is Aileen O' Mahony and I have been working at MDI as Administration Co-ordinator since June 2nd 2004.

I am based in the Dublin office and my role involves the daily management and development of the administration systems within MDI. This includes, overseeing the office administration, the human resource function and working on financial budgets for the organisation.

The position of Admin.Co-ordinator is a new one in MDI, responding to the needs of an expanding and developing organisation. It is a very exciting time to work with MDI and I am looking forward to the challenge.

I hope to meet you all at the various MDI gatherings over time. Goodbye for now, I hope you enjoy the rest of the summer.

I can be contacted in the office at 01-872 1501, freephone 1800 245 300 or by email at aileen@mdi.ie.

**Aileen O'Mahony
Administration Co-ordinator**

Karen Leonard

Youth/Respite Worker – Eastern Region

Hi everyone.

My name is Karen Leonard. I have recently been appointed as the Youth/Respite Worker for the Dublin area. I am from Dundrum in Dublin where I grew up with my two brothers and my sister.

After my Leaving Cert. in 1998 I studied Social Care in Inchicore College. Following on from that I did a degree in Psychology, which I have just finished. During my studies I have done a lot of placements and voluntary work which have included working with disabled students in Ballinteer Community School, working with children with autism in St. Ita's Special School and working as a Care Assistant in Our Lady's Hospice among others.

I hope to be able to use my past experience to provide you with a lot of youth clubs that you will find enjoyable. I would also love to hear from you about what types of youth clubs you would like me to organise in the future so I can make sure we have something for everyone.

I would like to take this opportunity to thank Noeleen and all the other youth workers for all their help and support especially on the camp.

I look forwards to meeting all of the members and families from the Dublin area in the near future.

**Karen Leonard
Youth/Respite Worker
Eastern Region**



Family Support Workers and Youth/Respite Workers Timetable and Contact Details

July 2004

Name	Telephone	Office Address	Work Days	Area Covered
Family Support Workers				
Catherine Logan	086 3834428		Monday, Tuesday Wednesday	Northern Area Health Board (Northside of Dublin) & part of South Western Area Health Board (South West Dublin, Kildare, Wicklow)
Eithne Diamond	086 3830966		Monday, Tuesday Wednesday	East Coast Area Health Board (South Dublin Coast, Wicklow) & part of South Western Area Health Board (South West Dublin, Kildare, Wicklow)
Margaret Goode	086 6066105 046 9280026	MDI Office North Eastern Health Board Region, Climber Hall, Kells, Co. Meath	Monday, Tuesday Wednesday	North Eastern Health Board Region (Cavan, Monaghan, Louth, Meath)
Catherine Jones	086 3834426 046 9280026	MDI Office North Eastern Health Board Region, Climber Hall, Kells, Co. Meath	Monday CRC Clinic Tuesday, Wednesday Last Thursday of every month Beaumont Clinic	Family Support Link & Clinic Support Person
Marie Kealy	086 6066107	C/o Bishop Birch Training Centre Waterford Rd. Kilkenny	Tuesday, Wednesday (am) Thursday	South Eastern Health Board (Carlow, Kilkenny, Waterford, Wexford & South Tipperary).
Caroline Moran*	091 563000	MDI Office Ruxton Court 35-37 Dominick St Galway	(Currently on maternity leave until end of Sept.)	Western Health Board (Galway Mayo Roscommon) and part of Midlands Health Board (Longford Westmeath Offaly)
*Fintan Flannery is also covering part of Caroline's area until the end of Sept. (Longford and Western Region) +Willie Egan is covering the Midlands region except Longford.				
Noreen O Grady	086 3834427		Monday, Tuesday Wednesday	Mid Western Health Board. (Limerick, Clare & North Tipperary).
Trudy Renshaw	086 3899266 021-4348442	MDI Cork Office Unit 24 Westside Centre Model Farm Rd, Cork	Monday/Friday	Southern Health Board (Cork & Kerry)
Fintan Flannery	086 3899279 071 9140210	MDI Office Unit 4 Business Cntr Market Yard, Sligo	Monday, Tuesday Wednesday	North Western Health Board. (Donegal, Sligo, Leitrim).
+Willie Egan	086 3899279			Midlands region except Longford
Youth Workers				
Karen Leonard	086 6066109	Based in Dublin	Monday/Friday	Eastern Regional Health Authority
Brenda Hopkins	086 6066108	Based in North East	Monday/Friday	North Eastern Health Board Region
Sinead Kenny	086 3899285	Based in Midlands	Monday/Friday	Midland Health Board
Joanne Cleary	086 3899286	Based in Galway	Monday/Friday	Western & part of Midland Health Board
Mary-Rose Howell	086 6066104	Based in Cork	Monday/Friday	Southern Health Board
Head Office Contact Details				
Joe Mooney Director	01 8721501 - Phone 1800 245 300 - Freephone 01 8724482 - Fax	Muscular Dystrophy Ireland 71/72 North Brunswick St. Dublin 7	Office Hours: 9am -5pm, Monday - Friday Emergency phone 086 2219641	

MDI Dublin Branch

Family Barbecue



Sunday 25th July 2004 – 2-6pm

Lucan Youth Centre
Primrose Lane
Lucan Village
Co Dublin

Food and soft drinks supplied



Directions

Directions (from Dublin City Centre) Take N4 (Galway Road). Take the slip road at the Foxhunter Pub (follow signs for Lucan Village). At top of slip road, turn right and go over flyover, then turn left. Drive past Courtenys Pub (on your left) and at the Garda Station take the next left (a small lane). This is Primrose Lane. Lucan Youth Centre is at the end of this lane.

All Welcome