

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

Editorial

Hello again,

Welcome to the May issue of our Newsletter. It's a sure sign that summer time is nearly here when the MDI camps get started, and already the first camp for adult members has just finished in Galway - I hear a good time was had by those who attended. We'll have a full report on camps in the next issue.

Karen's research page in this issue looks at the use of steroids in Duchenne muscular dystrophy and presents findings from a conference in Holland recently (see page 2).

There is also a very interesting article on page 2 about a study which is taking place in the South West of England entitled "BLEEP" (Being Like Everybody Else Project).

"There are 14 neurologists in Ireland compared to 123 in Albania [similar population]". This is just one startling statistic which was stated at an Information / Awareness meeting on Neurology which was organised by Muscular Dystrophy Ireland, the MS Society of Ireland and Headway Ireland (see page 3).

On page 4 you will find details of a leadership development course (being run by Rehab Care) aimed at adults with disabilities, which may interest some of our members.

The Woman's Mini Marathon takes place on Bank Holiday Monday, 7th June and (if you are running in this event) we would welcome your support. See page 7 for more details.

Two days later, on Wednesday 9th June MDI are hosting an All Ireland Symposium on Neuromuscular Conditions for Health Care Professionals, (details also on page 7).

This newsletter unfortunately has less pages than usual, as there were just a few articles sent into me from Branches this time around (which are included throughout). I would however, love to include more articles and news from around the country, so please send in news, view, pictures etc. The next issue is due out in July. I look forward to hearing from you.

Until next time, enjoy.

Hubert McCormack
Editor



Tony Farrell (Dublin) & Billy Daly (Cork) "having a cuppa" at an adult break in Co. Galway from 10th-14th May 2004



[Left photo] Sean Joyce from Galway (centre) pictured with his friend James (left) and Sean McGonigle from Dublin at the Chelsea / Everton match on Saturday 17th April in London.



[Right photo] Senan McGonigle (Dublin), Kevin & Sean Fitzsimons (Dublin), Rory, James (Jnr.) & James (Snr.) O'Donoghue (Kerrv). also pictured at the Chelsea / Everton match. The score incidentally was nil all.

Corticosteroid use in Duchenne Muscular Dystrophy

Corticosteroids, such as prednisone, its related compound prednisolone, and deflazacort, are used to try to prolong walking in Duchenne muscular dystrophy. However, there has not been agreement on the best dosage, the age to start taking these medications, or how to limit the potential side effects.

A report has been issued by the European Neuromuscular Centre (ENMC) after a conference in the Netherlands in which 35 participants from Europe, USA and Canada discussed new directions for corticosteroid use in DMD. The main conclusions of the group are that:

- there can “no longer be any doubt that the use of steroids in ambulant [walking] children with DMD alters the natural history of the condition”
- children treated with daily steroids are likely to walk longer, have improved respiratory function, may avoid the need for spinal surgery and might have better heart function than untreated children
- there are significant side effects associated with the corticosteroids prednisone and deflazacort, most seriously weight gain and decreased bone density
- alternatives to daily steroids, such as steroids given every other day or for 10 days followed by 10 days off, or on weekends only, as well as different dosages, might mitigate side effects and still provide benefits
- a large scale clinical trial to test the relative merits of different approaches to steroid use in urgently needed
- in advance of this trial, boys with DMD on steroids should be encouraged to be as active as possible and to maintain proper levels of vitamin D and calcium to avoid bone loss, as well as avoid sweets and fast foods to control their weight.

For more information, check www.mdusa.org and a copy of the ENMC report is available from www.enmc.org/workshops/reports.cfm?p=157

Being Like Everybody Else

BLEEP (the Being Like Everybody Else Project) is a study taking place in the South West of England, looking at how children with a neuromuscular condition may be socially excluded at school and what effect this might have. Tricia Nash, Senior Research Fellow at Exeter University and Director of BLEEP, said that “The idea of BLEEP came to us when we were working on another project about the medical support at school for children with serious chronic illnesses. We realised that many of the children we were interviewing were also experiencing social exclusion at school which was having a significant effect on their quality of life at school or college.”

The research is focussing on 7-19 year olds, and young people are the main contributors although parents and school staff are also participating.

Tricia says “It’s given us a huge insight into what life is like for them and the sort of things they experience. Just about all of them do have difficulties at school or college and it’s pretty grim in a lot of cases. School trips are one of the biggest problems. Often disabled children are excluded because there’s no accessible transport or extra help. But there are also the day-to-day issues that can make a child feel excluded. Sometimes, for example, children in wheelchairs are not able to sit with their friends in class because there’s no room to manoeuvre the chair around the classroom. And some schools don’t have lifts so wheelchair users can’t use the classrooms on the first floor, where there may be special equipment, so they miss out on lessons such as IT and domestic science. Children in wheelchairs may also be excluded from PE because the school hasn’t adapted the class to suit the disabled child.”

When the research is completed, the aim is to produce a series of guidelines for schools and colleges on the inclusion of disabled pupils.

Young people in Ireland are undoubtedly going through similar experiences and it will be interesting to see how this project develops and how the guidelines could be applied to schools and colleges in this country. Look out for the results in the MDI newsletter when the project is completed.

Taken from Target MD, Issue 29, April / May 2004. Target MD is the newsletter of the Muscular Dystrophy Campaign, UK

Neurology.....The Forgotten Service in The South-East

“There are 14 neurologists in Ireland compared to 123 in Albania [similar population]” “Of this 14, there are **none** in the **south-east** [where there are **55,000** people with neurological conditions]”

These were just two of the startling statistics given by Dr. Brian Sweeney, Consultant Neurologist at Cork University Hospital, at a specially convened Information/Awareness meeting at the Woodlands Hotel, Waterford on Monday 19th April.

The meeting was organised by Muscular Dystrophy Ireland, MS Society of Ireland and Headway Ireland, three of the many organisations which support members with various neurological conditions.

The purpose of the meeting was to increase awareness among local Public Representatives of the great need for a Neurology Service in the South East as stated in the Comhairle na nOspideal Report 2003 which recommended that 3 neurologists be appointed to Waterford Regional Hospital.

Speakers at the conference included Dr Sweeney who addressed the meeting on Neurological Services in Ireland. A number of individuals affected by a Neurological Condition and family members also gave heart-rending accounts of frequent, long, painful 3-hour trips to Dublin for a 15-minute consultation before beginning the hazardous journey home.

One member [Anna Fenlon, who has Multiple Sclerosis] spoke of the distress and fatigue which the long trips to Dublin caused her. These trips forced her to make the decision not to travel to Dublin to see a neurologist and she has not seen a neurologist for over 10 years now.

A Questions and Answers session followed - the panel of which consisted of Dr. Sweeney, Dr. Orla Hardiman [Consultant Neurologist, Beaumont Hospital, Dublin]; Dr. Riona Mulcahy, Consultant, Waterford Regional Hospital, Ms. Cora Long and Mr. Gus Byrne, both members of the South Eastern Health Board.



The Steering Committee

Pictured at the Information/Awareness meeting on the lack of Neurology Services in the South East are (from L-R): Jo Ashby, MS Ireland; Olive Murphy, MS Ireland; Willie Egan, MDI; Katie Hourigan, MS Ireland; Mary Keane, MS Ireland and Clíodhna Carroll, Headway Ireland

The meeting concluded with the message “All we in the South-East are looking for is our FAIR SHARE of the Health Budget for Neurology Services”

For further information, contact:

*Willie Egan, Muscular Dystrophy Ireland,
Tel: 087 6329622
MS Society of Ireland, Kilkenny Office
Tel: 056 7751522
Clíodhna Carroll, Headway Ireland,
Tel: 056 7786240*

Partners in Policymaking

Partners in Policymaking is a leadership development course aimed at adults with disabilities and parents of a child with a disability. The aim of Partners in Policymaking is to give people the opportunity to develop the skills and knowledge they need to improve services and build more inclusive communities.

This course, which is being run by Rehab Care will commence in June 2004 and will run over 8 weekends, one per month for 8 months. The History of Disability; National Disability Policy; Communication Skills; and Assistive Technology are just some of the topics which will be included.

There are 30 places available on the course, which will be held at Roslyn Park, Sandymount, Dublin 4 and accommodation will be provided in nearby Bewley's Hotel, Ballsbridge, Dublin. All meals and accommodation will be free to course participants.

For more information and an application form contact the following:

Arlene Connor, Tel: (01) 2057350
 Email: arlene.connor@rehabcare.ie
Maria Lynch, Tel: (01) 2057350
 Email: maria.lynch@rehabcare.ie

It's a Girl!



Congratulations

to Caroline Moran, FSW for the West & Midlands, and her husband Stefan, on the birth of their new baby girl recently. MDI would like to wish Caroline, Stefan and Baby Eva every happiness for the future.

Sugar and Spice & everything nice.

News from the Mid West Region

Hi, Noreen O'Grady here - Family Support Worker for Mid-West area. On Saturday 3rd April I called a support meeting in Limerick for all our members throughout the mid-west region.

The meeting was held in St. Gabriels CRC, Dooradoyle and was well attended. After introducing myself, I then introduced our Director Joe Mooney, Joesphine our part-time care worker, and the various volunteers present.

Our special guest speaker was Mary Sheehy from the Citizens Advice Centre who gave a very informative speech on "Entitlements for People with Disabilities". Plenty of questions and answers then followed.

While the meeting was taking place, the children present were entertained in the play-area by Josephine and the volunteers.

After a short break for refreshments, we were then entertained by a magician, who was a great hit with both young and old. The laughter of the children could be heard throughout the building. Everyone gave him the "Thumbs Up".

A special thank you to St. Gabriels Centre for the use of their premises. Thanks also to Joan (MDI Youth Worker from Galway), who travelled down to help us. The day was very successful and we hope to run another support meeting in May.

Noreen O'Grady



Younger members of MDI being entertained by a Magician at the MDI support meeting in Limerick

Sportslink host Power Soccer Day

On 24th April last, MDI (in association with the Football Association of Ireland - FAI)) hosted another Power Soccer Tournament, this time in Sportslink, Santry, Dublin. The following article, which was recently published in the Northside People Newspaper in Dublin, demonstrates the continuing success and popularity of this sport.

Around 20 young wheelchair users took part in a Power Soccer Day in Sportslink, Santry last weekend.

The event was held in association with Muscular Dystrophy Ireland (MDI) and the Football Association of Ireland (FAI). The power wheelchair users took part in skills training and demonstration games with an exciting tournament rounding off the day.



Alan Conboy from Galway and Sean McGonigle from Dublin pictured "on the ball" at the Power Soccer Tournament in Sportslink in Santry

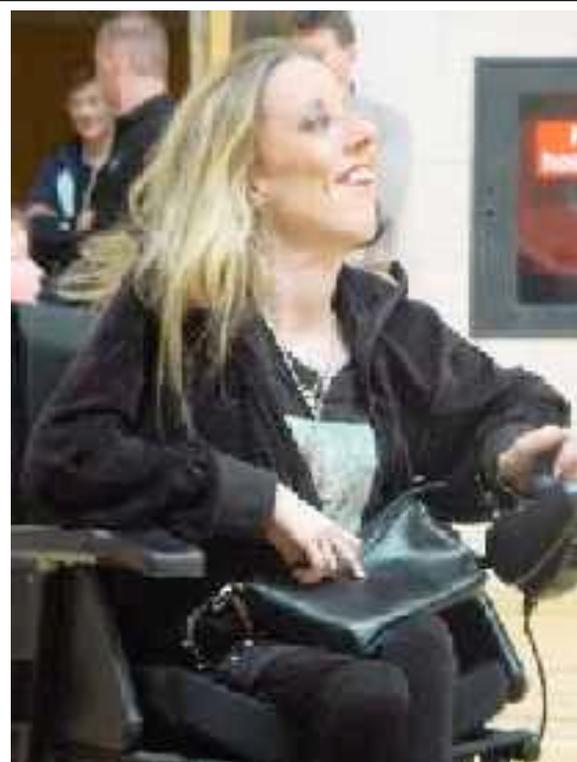
Power Soccer is an extremely competitive sport that has been available in other countries for the last 14 years but is only now exploding onto the Irish sports scene.

It is a team sport played by individuals with various disabilities. It is unisex by design, and male and female participants are often on the same team as well as opposing sides.

The game is usually played in a gymnasium on a regulation basketball court. Two teams of four power chair users attack, defend, and

manoeuvre an oversized soccer ball in an attempt to score points on a goal. The game is similar to the non-stop action seen in a typical indoor soccer game.

Power Soccer is regarded as an action-packed team sport that combines the skill of the wheelchair user with the speed and power of the chair itself, to participate in an extremely challenging game very similar to soccer.



Sammy Brill from Westmeath "checking out the score" at the Power Soccer Tournament in Santry!

It is the first competitive team sport designed and developed specifically for power wheelchair users. Participants include persons with quadriplegia, multiple sclerosis, cerebral palsy, head trauma, stroke, and other disabilities.

The will to win, the competitive challenge, teamwork and the total competitive spirit of an athlete is in no way limited or diminished because they use a wheelchair.

As in all sports, win, lose or draw, the thrill and joy is in playing the game.

Dublin Branch Table Quiz raises €1,100.00



MDI would like to thank Jean Butterly and her friend Karen and Ephraim and Fran Purcell (above) for organising the Dublin Branch Table Quiz on 6th April in the Spawell Sports Club, Templeogue. A great night was had by all and €1,100 was raised for the Dublin Branch. Well done and thanks to everyone concerned.



Thanks also to Sean & Mairead Farrell from Dublin (above with their family) for organising spot prizes.



Micheal Doyle from Dublin and MDI's FSW for Dublin, Eithne Diamond (two of the tie break winning team members) pictured at the Dublin Branch Table Quiz

Midlands trip to Disney

On the 3rd of April last, a group of young members and young at heart parents set out from the midlands branch of MDI to see Mickey and the gang at the Point Theatre Dublin.



There were plenty of old favourites such as Mickey, Minnie, Goofy, Daffy and Pinocchio. And there were also plenty of new favourites such as Woody, Buzz Light Year and the gang, Aladdin, Beauty and the Beast, Jungle Book and A Bugs Life.

The show was amazing and a great time was had by all. I think the adults enjoyed the show just as much as the younger members !! We can't wait to go again.

Sinead Kenny
Youth Worker – Midlands

Golf Classic



Proceeds to:

Muscular Dystrophy Ireland

VENUE: Bray Golf Club
(New Course)

DATE: Friday 28th May 2004

PRICE: €450 - per Team of 4

Includes a meal and an opportunity to win top prizes. To register and for further information contact Steven in MDI on (01) 8721501

Women's Mini Marathon

Why not join the MDI Team



Have you registered to participate in this year's Dublin

Women's Mini Marathon

on Bank Holiday Monday

7th June 2004

If so, why not run for

Muscular Dystrophy Ireland

We will be meeting afterwards in Café en Seine on Dawson Street after the event for a drink. For further information, sponsorship cards and

T-Shirts, contact Steven in the MDI office on 1800 245300 or E-mail steven@mdi.ie

Your support would be much appreciated

All Ireland Symposium on Neuromuscular Conditions for Health Care Professionals

Wednesday 9th June 2004

**Red Cow Moran Hotel & Conference Centre,
Naas Road,
Dublin 22**

Muscular Dystrophy Ireland in association with the Muscular Dystrophy Campaign, UK, will hold a one day symposium for health care professionals on muscular dystrophy and related neuromuscular conditions.

Topics covered will include occupational therapy, physiotherapy, neurology and research.

Cost: €20.00 / £14.00 per person (lunch & refreshments included).

For more information contact Karen in the MDI office on (01) 8721501 or email her at karen@mdi.ie

Reminder

Membership subscriptions for 2004 are now due. If you haven't already paid your subscription this year please we would remind you to do so at your earliest convenience.

If you have paid your membership for this year, thank you.