MDI Members Emer O’Sullivan and Aoife McNicholl enjoying a cocktail while on camp in Galway.
On the 11th June last, Muscular Dystrophy Ireland (MDI) was delighted to learn of the decision by the Health Service Executive to approve Spinraza, the only treatment on the market for the rare muscle-wasting condition spinal muscular atrophy (SMA), after a lengthy campaign by SMA Ireland, families of children living with SMA and members of MDI.

The HSE’s leadership team (in early June 2019) decided to reimburse the drug, effectively overturning a negative recommendation by its drugs group last May.

The drugs group voted by a narrow majority in May against reimbursing Spinraza, despite a revised price application by the manufacturer, Biogen.

The UK’s national health service subsequently approved the drug, leaving Ireland in an “isolated position”, HSE director general Paul Reid acknowledged in an appearance before the Oireachtas health committee.

Earlier this year, the HSE said the drug would cost about €600,000 in the first year to treat each of the 25 Irish children with the condition and €380,000 a year thereafter, “with an estimated budget impact in excess of €20 million over a five-year period”.

Biogen subsequently issued a revised price proposal which it said was in line with the final price negotiated in other European countries that have approved the drug. Spinraza is approved in 26 countries around Europe with just Estonia rejecting it.
As part of its submission, Biogen has previously provided the HSE with pricing for its portfolio of biosimilars - like-for-like therapies for expensive biologic drugs that have come off patent - that it says would offset the cost of Spinraza.

Families of children with SMA protested outside Leinster House in February, with members of most Opposition parties prominent among the attendance.

With just €10 million available for innovation in drugs this year, the HSE had spent virtually all of its new medicines budget by February.

After years of campaigning by our members and associates, this decision by the HSE has been welcomed by Muscular Dystrophy Ireland (MDI) and in particular by families of our younger members with SMA. For the wider SMA community however, the campaign still goes on because Spinraza has yet to be approved as a treatment for adults with SMA in Ireland, which we at MDI view as age discrimination and upsetting for the 34 people whom we have registered on our database with SMA.

*Have you added your details to the SMA Ireland Database?*

Over the past 18 months SMA Ireland has been working to compile a comprehensive registry of people living with SMA in Ireland. Have you added your details to this Database?

It has been an ongoing problem as SMA Ireland seek services and treatments for people with SMA that there does not seem to be any reliable information available regarding numbers of people living with SMA in Ireland. This voluntary database aims to gather information on individuals with SMA (age, locations in the country etc.) to help ensure they are properly represented.

SMA Ireland is therefore asking people for their contact details so they can keep you informed of what’s going on with SMA in Ireland and other issues that might affect you. This will never be shared with any third party.

To register your details please contact SMA Ireland via their website: [www.smaireland.com](http://www.smaireland.com) or contact Jonathan O'Grady directly at [jonathanogrady@smaireland.com](mailto:jonathanogrady@smaireland.com) or telephone 087 229-1850.
On Tuesday, 11 June 2019, the HSE/Department of Health agreed to grant access for the drug Nusinersen (Spinraza) on an exceptional and individualised basis for people under 18 years of age with Spinal Muscular Atrophy (SMA) Type I, II or III. For the 25 children in Ireland with SMA, this is of course very welcome news following months of uncertainty and worry. However for the wider SMA community it feels like a hollow victory, as the less than 25 adults with SMA in Ireland have been let down by this short-sighted decision.

Commenting on the age-related access criteria, SMA Ireland spokesperson Jonathan O'Grady said,

"The 18 age cap is a case of blatant discrimination. We're not talking about a required level of maturity, such as being able to vote. We're talking about a line in the sand that effectively excludes a small minority simply because it is economically convenient.

The HSE argues that trial data as of yet provides insufficient evidence for adults. However Spinraza has been approved in all EU countries, except Estonia where it is still under review. In the vast majority of these countries, age is not used as a barrier to access. These health authorities, like SMA Ireland, believe that it is most unlikely that the benefits of treatment cease just because the patient has turned 18. SMA Ireland fully accept that there needs to be some criteria for access to Spinraza, but an age limit is crude and unfair.

I am of course thrilled that a child born today with SMA in Ireland will have access to Spinraza. This will undoubtedly reduce the worst effects of the disease and give this child every opportunity to lead a full and happy life. But think about it; for someone over 18 living with SMA in Ireland today, they have survived because they maybe have a slightly less aggres-
On 25th February last, Muscular Dystrophy Ireland was very happy to acknowledge the HSE's decision to reimburse Translarna for the treatment of Duchenne Muscular Dystrophy. This decision means that five Irish patients with DMD will now become eligible to receive the new drug.

Translarna, developed by PTC Pharmaceuticals, is a treatment for a specific form of Duchenne Muscular Dystrophy. It applies to patients with a specific genetic defect called a ‘Nonsense Mutation’ in the dystrophin gene, and who are aged five years and older and still able to walk.

The decision to reimburse Translarna came almost five years after the drug first received conditional approval from the European Medicines Agency, and over three years since the first submissions were made for the drug reimbursement in Ireland.

Elaine McDonnell, CEO MDI:
“This has been a long and difficult journey for everyone involved in the effort to have Translarna available in Ireland, and after years of hard work we are delighted to see that a positive outcome has finally been achieved.

We want to acknowledge and congratulate everyone who has contributed to this success, including Dr. Declan O’Rourke and his team, the numerous politicians and journalists who have helped to publicly highlight Translarna, and Clair Kelly who played a key role on behalf of MDI during her time with us.

Most importantly however are the families who led the campaign by opening their lives to the public, to the scrutiny of the HSE decision makers, and endured a long and trying process for which they have now been rewarded.

We hope that the families will now see the same outcomes and benefits that many of their peers across Europe, who have already accessed Translarna, have experienced. And that this process will provide a pathway for other treatments which are already, or will soon be, available for other forms of Muscular Dystrophy.”
On Saturday the 22nd of June, MDI held our annual general meeting in the Red Cow Moran Hotel, Naas Rd, Dublin. The morning began with the business of the day, the AGM itself. The Annual Report and Audited Accounts for year ending 2018 were presented to the meeting. Both reports (and previous years reports) can be viewed on the MDI website - see: [www mdi ie mdi annual reports and audited accounts html](http://www.mdi.ie/mdi-annual-reports-and-audited-accounts.html). The elected Board of Directors for the current year were follows:

**Chairperson:** John Roche  
**Vice Chairperson:** Grace Greene  
**Secretary:** Hazel Bridcut  
**Treasurer:** Ephraim Purcell  
**Board Members:** Kenneth Rowan

After lunch, guest speakers were invited to update members on current projects and/or services.

The first speaker up was MDI’s Fundraising / PR Coordinator, Patrick Flanagan, who updated members on the MDI Strive Project which is a new initiative for members to support personal development and social engagement, with a particular emphasis on people with Duchenne muscular dystrophy.

Assistive Technology for people with disabilities was the next topic on the agenda and Sean O’Donnell (Sean O’Donnell Electrical) and Brian Dillon (HouseMate.ie) both provided details of the various environmental controls available to make one’s home more user friendly for people with disabilities.

And finally, Caroline Gardner from Quality Matters updated members on how MDI’s five year strategic plan is progressing and where it is at now. Copies of all presentations will be available soon. Please contact MDI if you would like a copy of same.

Thank you to all members who attended the AGM and to our speakers on the day.
Introducing MDI’s New Head of Services, Ashling Kennedy

Ashling joined MDI in June this year as Head of Services. Ashling has a background in Management, Psychology and Counselling and Psychotherapy and has worked in the non-for-profit sector in community development with disadvantaged communities for over 20 years. Ashling previously worked for the Irish Foster Care Association for over 5 years in a similar role providing services using a holistic-focused and member-centered approach and worked with Special Olympics Ireland previous to that, for over 7 years.

Ashling will be responsible for implementing aspects of the strategic plan related to the services and for driving forward the services agenda to ensure the right services are available and resourced for members and their families, striving for better outcomes and supports for all our members.

We at Muscular Dystrophy Ireland would like to welcome Ashling to our organisation and we wish her well in her new role within MDI. Ashling will be based in our Head Office in Chapelizod, Dublin and you can contact her at MDI on (01) 6236414 or 086 8511207 or email: headofservices@mdi.ie.

MDI would like to thank Giovanni Stimamiglio from Italy (pictured top left with MDI staff) who was on work experience at MDI for the month of June. Giovanni assisted all staff in Head Office with various tasks during his time with us and was a great help to us all. We wish him well for the future.

In 2017 and 2018, Muscular Dystrophy Ireland’s former Information Officer, Clair Kelly was extremely involved with the draft of this Charter and MDI are just one of the 35 Member Organisations who are signatories of this Charter, which calls for greater involvement in the ‘Medicines Assessment & Reimbursement’ process in Ireland. The Charter also calls on the government to improve the transparency, accountability and communication on how medicines are assessed & reimbursed by the State.

The Charter, co-ordinated by the Irish Platform for Patient Organisations, Science & Industry (IPPOSI), with the support of the Medical Research Charities Group (MRCG) and Rare Disease Ireland (RDI), sets out 29 actions that the relevant State agencies (Department of Health; Health Service Executive, National Centre for Pharmacoeconomics) should take to inform and include patient perspectives at every stage of the process.

This Charter provides a collective and holistic response to address the many Irish patient concerns expressed about levels of transparency, accountability, quality and fairness in the Irish Health Technology Assessment (HTA) and post-HTA process.

It was developed with a cross-section of the IPPOSI patient membership as well as the support of the Medical Research Charities Group (MRCG) and Rare Disease Ireland (RDI). It is designed to promote patient empowerment through effective partnership between patient communities and the Irish state agencies responsible for medicines assessment & reimbursement.

For further details see: www.ipposi.ie/2019/02/20/patient-charter-published/
Living Well with a Long Term Health Condition

A self care group programme in the South East for people living with a Long Term Health Condition.

Living with a long term health condition is your community based programme that was originally developed at Stanford University.

The group programme runs for 6 weeks, one session per week. Each session lasts 2.5 hours. Each programme is facilitated by certified leaders.

The skills you will learn include:

- Problem solving and decision making.
- How to set management goals.
- Managing your medication.
- Communicating effectively with your family, friends, and healthcare team.
- Relaxation and managing stress.
- Healthy eating, weight management and appropriate exercise techniques.
- Managing pain, fatigue and difficult emotions.

Contact: Lana/Denis on 086 816 3772
Book via Eventbrite: https://se-livingwell-wexford.eventbrite.ie

Start Date: TBA
Venue: Ramsgrange Resource Centre

Fee: €20 for 6 sessions & course handbook
In June, ILMN (formally Centre for Independent Living) launched a Leader Manual which is designed as a support for people with disabilities who have a PA service, want a PA service or who would like to know more about Independent Living. Prior to this publication, months earlier, ILMI also produced a very informative leaflet entitled “Achieving a right to personal assistance in Ireland”, which we have included below. We at MDI believe many of our members will find this information very helpful in their ongoing quest to secure appropriate and secure Personal Assistant Services, which sadly is an uphill battle for many. For a copy of the Leader Manual or further information visit: www.ilmi.ie, email: info@ilmi.ie or call: (01) 8740455

Achieving a right to personal assistance in Ireland

Prepared by:
Bearnairdín Nic Aogáin, Rory Knight, Mary Melvin, Teopista Nanyanzi, Cliona de Bhailís and Professor Eilíoniór Flynn

Independent Living is about having the freedom to have the same choices that everyone else has in housing, transportation, education and employment. Independent living is about choosing what aspects of social, economic and political life people want to participate in. Independent living is about having control over your life, to have a family, to get a job, to participate socially and to realise your goals and dreams. For many disabled people, Independent Living can best be achieved by the employment of Personal Assistants to provide supports where needed.

ILMI’s vision is an Ireland where disabled persons have freedom, choice and control over all aspects of their lives and can fully participate in an inclusive society as equals. We believe that a right to a personal assistance service for disabled people is fundamental to achieving that vision.
The Personal Assistance Service (PAS) is a tool that allows us to live independently. The PAS enables us to do all the tasks that we cannot do for ourselves. It provides us with the freedom and flexibility we need to live our lives as we chose. A Personal Assistant (PA) is hired to assist us with a range of day-to-day tasks that we cannot physically do for ourselves.

With PAS we are in control and direct the PA to carry out tasks both inside and outside of the home, including personal care, domestic duties, assisting in day-to-day tasks such as shopping, support in the workplace or socialising. A PA does not “look after” or “care for” us. We delegate these tasks to our PAs and in doing so take back control of our lives.

In March 2018 Ireland formally ratified the UN Convention on the Rights of Persons with Disabilities (CRPD). Under Article 19 of the CRPD disabled people have the right to live in the community and have access to a range of in-home and other supports, including personal assistance, to support this.

Currently there is no legal right to personal assistance in Ireland. Those in need of this support often find the application process problematic, as there is no standardised procedure and those in receipt of this support do not have any security regarding the continuation or extent of their service due to lack of legislative protection.

In 2017, 84 percent of those in receipt of a PA service received less than three hours a day and 42 percent of these people were in receipt of between one and five hours a week. This is only an average of 42 minutes a day, despite there being 1,440 minutes in a day and disability being a 24-hour affair.

As far back as 1996, it was identified that an average need for 10 hours of PA service per person per week could only respond to essential personal care needs, not quality of life requirements and it would certainly not enable full active participation in the community.

Sweden has long been regarded as the ground-breaking country and ‘gold standard’ for personal assistance. It remains the only European country which legally confers a right to personal assistance, although there is some legislation in this area in many countries, such as Denmark, France, Germany, Latvia, Norway, Serbia, Slovakia, Spain and the UK.

**Achieving a Right to Personal Assistance in Ireland**

shows that introducing stand-alone legislation is the most straight-forward way to recognise the right to personal assistance for disabled people. The comparative research conducted for this report shows that legislation will need to focus on the full, active participation of disabled people in society, including in education and employment.

This must be based on a comprehensive assessment of the individual’s needs to determine the amount of personal assistance an individual will receive in order that they have choice, control and freedom to participate in society as equals.
Harley Davidson Raffle Results 2019

First Prize: Harley Davidson Street Rod. Winner: Cathal Hayes from Sixmilebridge, Co. Clare.

Second Prize: Weekend for 2 in the Brehon Hotel, Killarney. Winner: Rudolph Ness, Killarney, Kerry


Since 2006, The Gleneagle Hotel in Killarney, Co. Kerry and Ireland Bikefest have been supporting Muscular Dystrophy Ireland with our Awareness and Fundraising activities. This fundraising initiative has gone from strength to strength each year and has raised over €100,000 for MDI since its conception. The 2019 rally of the now well-established "Ireland Bike Fest" took place from 31st May to the 2nd June 2019 and was another roaring success! The total raised at the 2019 event was over €10,500.00.

We would like to thank the Staff and Management of the Gleneagle Hotel in Killarney for once again inviting MDI to participate in this event. We at MDI are delighted to have been charity partners at this fabulous festival since the first BikeFest in 2006 and long may this association continue. Thanks also to everyone who sold and bought tickets and helped to make this fundraising initiative for MDI a great success. Your support is very much appreciated.

Thank you to everyone who took part in the VHI Women’s Mini Marathon on the 2nd June for MDI. If you haven’t already sent in your proceeds from this event we would appreciate it if you could do so as soon as possible. All money raised will be used to fund MDI’s respite support services. Pictured below are some of the participants on the day. Thanks again for your ongoing support and well done!
Recent Fundraising News and Updates

Jennifer’s Cakes Makes €500 for MDI

I decided to do a Bake/Cake sale fundraiser in aid of Muscular Dystrophy Ireland as I am one of many members who have had some very enjoyable days out with this very worthy organization and I also decided to do the fundraiser as part of my practical achievement task for school.

The Bake/Cake sale was held in my school St. Brogans College, Bandon, Co. Cork on Friday the 7th December 2018 from 11:05am-11:20am. Thanks to all my classmates, teachers, SNA’s and all the staff at St.Brogans for helping me with the Bake/Cake sale by donating and baking some treats and also for being very supportive of the event.

Jennifer O Connor, Bandon, Co. Cork

Adam Cosgrove Memorial Ball raises over €11,400 for MDI

MDI would like to share a huge thank you with Carole Cosgrove and family who presented MDI with a cheque €11,456.02 last March. This money was raised at the Adam Cosgrove Memorial Ball weeks previously.

MDI was honoured to be a part of the event alongside the Jay and Ellie Foundation, and we would like to acknowledge the amazing work and support shown by everyone involved!

Gael Scoil Dundalk

The 6th Class students of the Gael Scoil Dundalk raised €1,185 for Muscular Dystrophy Research, holding a Bake Sale in their school. Go raibh mile maith agaibh go léir!
Recent Fundraising News and Updates

St Mary’s National School Knockbridge
Thank you to the staff and students of St Mary’s National School Knockbridge who raised €350 for MDI and presented the cheque to MDI’s CEO Ms. Elaine McDonnell in early June.

Kiltale Walk and Talk
Over €4,000 was raised by the Kelly family and Kiltale GAA and Community Group for MDI, from their Walk & Talk fundraising held during the May Bank Holiday weekend.

We were delighted to welcome Orla Byrne to MDI Head Office in June where she presented MDI with a donation of €410. Orla, from Ratoath, Co. Meath, did a Parasail for MDI as part of her Transition Year fundraising.
Recent Fundraising News and Updates

**Dundalk IT 10k**

A big thank you to Sharon Baldwin from Dundalk (centre) who along with her friends, raised €2,720 for MDI in this year’s Dundalk IT 10k Fundraising event.

**Waterford Golf Classic**

€3,320 was raised at this year’s Waterford Golf Classic for MDI. Thank you to organiser Jim Kealy, as well as Williamstown Golf Club for hosting the event. Thank you as well to the many prize and event sponsors who helped make the event such a success.

**Wonderful Wombles**

Thank you to the staff and families of the Wombles Creche in Lucan who held a Pyjama Party event for MDI and raised €2,189.50.
On Monday 20th May 2019, Ireland Powerchair Football team departed Dublin to travel to Pajulahti, Finland to play in the EPFA Nations Cup 2019. Ireland needed to finish in one of the top five spots to qualify for the World Cup in 2021 which will take place in Australia.

The teams that took part in the Nations Cup were: Austria, Denmark, France, Northern Ireland, Finland, England and Ireland. All games were played in the Olympic Village, Pajulahti, a very impressive set up, located in an amazing setting.

In the group stages, Ireland won against Austria, Northern Ireland and Finland and lost games to France, Denmark and England. In the semi-final, Ireland were defeated by current world champions France by a score line of 6-0. This left Ireland playing for a bronze medal match against Denmark. In a close match, the Danes took an early lead which they held till the last minute before Ireland’s Tom Donogher scored to make it 1-1. In extra time, once again Tom Donogher scored in the last minute to make it a 2-1 victory for the Irish. Huge celebrations from the Irish bench and supporters took place. The final placings were: France: 1st, England 2nd, Ireland 3rd, Denmark 4th, Northern Ireland 5th, Austria 6th and Finland 7th. With Ireland finishing third in Europe, it meant that we qualified for the world cup in 2021. I was the youngest player on the squad in Finland and I really enjoyed the trip and playing in my first senior tournament. Our rooms were amazing and the facility we stayed in was amazing.

Many thanks to Donal, John and Robbie (Coaches) and supporters for making the trip memorable and for keeping us going. Anyone who would like to take part in Powerchair Football can contact Patrick Flanagan from MDI for details or search the AIPF website – www.aipf.ie. We are all looking forward to the world cup in 2021.

Conor Troy (13)
Midlands Utd., Offaly
and MDI Member.

In June this year, I went to Malaga for a week with three of my closest friends. We stayed in the centre of Malaga beside the Cathedral. We were in walking distance from many attractions – just 10 a minute walk to the beach, 15 minutes to the supermarket and there were also lots of nice restaurants and gift shops close by. Our accommodation consisted of a “reasonably” accessible apartment – the only difficulty which I had was me having to get out of my wheelchair on a few occasions to negotiate a narrow doorway which was just slightly too narrow – not ideal, but I managed!

Malaga is a very accessible city. Every restaurant we went to had seating outside because of the amazing weather but I also had the option to eat inside as there was easy access. We went to the beach a couple of times during the week. The beach was really accessible as there was a ramp that went all the way down almost as far as the water’s edge. Before going on this trip, my best friend’s Dad made some beach wheels for my wheelchair so this made it much easier to push my chair on the sand. Overall it was a great holiday and I came home with lots of happy memories!

My trip to Malaga, by: Aisling McElligott from Offaly

Aisling McElligott (left) with her friends in Malaga
Remembering Passed Members

Sadly, since the last issue of this newsletter, we at MDI have been notified of the passing of the following members. We remember: Cathal Sheehan (Clare), Travis Foley (Louth) and Peter Bergin (Dublin). We would like to extend our deepest sympathies to the families and friends of the above members and indeed to all bereaved members of MDI. We would also like to remind you that MDI will always be here for you should you require any support or information in the future.

New weighing facilities at MDI

As many of our members are aware from our hospital appointments and visits to our local Health Centres etc., very often one may be asked: “what is your current weight?” This has become an even more prominent question in recent years when doctors and medical professionals are trying to establish people’s body mass index (BMI).

For many of us with disabilities (and particularly those of us with muscular dystrophy and other neuromuscular conditions) this can be a very difficult question to answer because we do not have the facilities to weigh ourselves on a regular basis. This may be because we cannot use a standard weighing scale to weigh ourselves, or we need to use a hoist to transfer from a wheelchair onto a “suitable” weighing scale, most of which are not usually accessible for us to use.

To help address this issue, MDI have recently purchased a full range of weighing scale equipment which can enable MDI members and people with disabilities to weigh ourselves accurately. The full selection of scales available at MDI are:

- a standard standing up bathroom scales
- a ceiling track hoist weighting scales
- a sit on chair weighing scales and
- a “drive on” weighting scales (where the individual remains seated in their wheelchair).

If anyone would like to use any of this equipment, please give the MDI office a call on (01) 6236414 and we can make arrangements for you to come in and use one or more of these weighing scales at a convenient time.

Gerrard Reilly Memorial

The annual Gerrard Reilly Memorial football tournament took place on Wednesday 5th June with schools from Crubany, Corlurgan and Killygarry National Schools in County Cavan raising €370 for MDI. We would like to thank all the pupils, staff and organisers for your ongoing support and remembering Gerrard in this lovely way.

Congrats Derek on your 80th Birthday

MDI would like to extend our best wishes to former MDI Director, Board Member, colleague and friend, Derek Farrell who celebrated his 80 birthday recently with family and friends. Pictured here are MDI members Jimmy Murray, Hennie Walsh and Hubert McCormack with Derek and his wife Olga (centre), celebrating this fabulous milestone.
Photos from recent MDI Camps, Social & Youth Activities
Photos from recent MDI Camps, Social & Youth Activities
To donate to MDI by text message at anytime you can

Text MDI to 50300 to donate €2.00

We would really appreciated your support.

100% OF TEXT COST GOES TO MUSCULAR DYSTROPHY IRELAND (MDI) across most network providers. Some providers apply VAT which means a minimum of €1.63 cent will go to MDI.

Service Provider LIKE CHARITY. Helpline: 01 4433890

MDI Member Des Mooney doing a spot of fishing while on camp. (indent picture) The “catch” displayed by Des and fellow MDI member Donal McTiernan.

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