The first ever All Ireland Research and Information Sharing Day hosted by Muscular Dystrophy Ireland and Northern Ireland Council of Muscular Dystrophy Campaign took place on the 21st September 2013 in City North Hotel, Gormanston, Co Meath. The day started at 10am and finished well after 5pm with attendees staying late to ask lots of questions. There was a great turnout with well over 100 delegates from both sides of the border. Child facilities were available on the day and afternoon workshops on child and adult physiotherapy and nutrition took place after lunch.

The day was officially opened by the **Lord Mayor of Drogheda, Cllr Richard Culhane** who extended a warm welcome to all and to our Northern Ireland friends in particular.

### Opening presentations

*Gary Kernahan, Head of Volunteer Fundrasing, Muscular Dystrophy Campaign (MDC)* represented Muscular Dystrophy Campaign saying it was a pleasure to talk about their work supporting families in Northern Ireland. This includes a call every 7 minutes to the help/information line, >1,000 publications, equipment grants, peer support, advocacy, ~£50 million to scientific research over 50 years with PhD studentships helping to support the next generation of scientists and 20 projects currently underway. Recent developments in Northern Ireland include the All Party Group and launch of the McCollum report [http://www.muscular-dystrophy.org/assets/0003/5328/Mccollum_Report.pdf](http://www.muscular-dystrophy.org/assets/0003/5328/Mccollum_Report.pdf) and increasing network of family funds. It was stressed that this was only possible due to MDC’s committed volunteers and supporters who raise funds for the charity.

*Ann Marie Coen, Information Officer, Muscular Dystrophy Ireland (MDI)* presented on behalf of MDI and explained our member-led focus with hugely popular youth and summer camps, respite support, fleet of 12 vans for transport services, equipment loans, family support, research funding, as well as advocacy and policy work information. It was highlighted that MDI’s home-from-home self-catering accessible apartment was booked out this summer and is in regular use all year around. A big THANK YOU was extended to all our tireless fundraisers.

*Maureen Brennan, MDI member and fundraising and PR intern with MDI* then commented on how she has been a member of MDI for 10 years and strongly advocated for the camps with the youth worker being a super approach to break a routine and build confidence. She felt it was great to be part of MDI where someone was always around for support.
Professional Talks

Professor Dominic Wells led the professional talks and started by saying it had been 11 years from he was last at MDI and he was pleased to be able to participate in this novel event. Professor Wells gave us an insightful snapshot of recent advances in experimental therapies for muscular dystrophy. Professor Wells also mentioned the disappointing results in GSK's recent press release (http://tinyurl.com/GSK-200913), but highlighted several promising pathways of treatment are making their way towards the clinic. There are a number of different approaches in or close to clinical trial. Several genetic therapies are very promising and better methods to make drugs work more efficiently are being developed.

Professor Dominic Wells, Professor in Translational Medicine, Royal Veterinary College, London. 'Recent advances in experimental therapies for muscular dystrophy'.

Dr Ronan Walsh described how the Republic of Ireland (similar to Northern Ireland) has insufficient clinical capacity with among the lowest neurologists per patient population in Europe. Despite this, he described the successful adult neuromuscular multidisciplinary clinic, in Beaumont Hospital ie: ‘a one-stop-shop’ that includes input from patient organisations such as MDI. The clinic also offers improved research opportunities and options for trial, Dr Walsh emphasised. He also highlighted how research shows that multidisciplinary clinics result in improved treatment and survival for patients. Dr Walsh closed by saying, "we need more days like this!"

Dr. Ronan Walsh, Neurologist, Beaumont Hospital, Dublin. 'Neuromuscular Conditions in Ireland – where are we now?'

Professor Richard Costello enthusiastically explained why it is important to see the breathing team. Professor Costello explained why breathing can be a challenge with sleep problems, daytime weakness, poor strength of speech, difficulty chewing/swallowing, chest infections, poor cough strength etc. Patient-focused tests are very important at clinic. Several options to improve the quality of life for individuals were discussed, including breath stacking with an ambu-bag, cough assist machines, non-invasive ventilation at night, and the relatively new approach of mouthpiece
ventilation for the daytime, which have proved real game changers. It was suggested that a chest infection needs at least three main things, (1) a plan, (2) antibiotics and, (3) cough bottle / cough assist / breath stacking.

**Dr Stela Lefter** is conducting a MDI and Genzyme funded study to find the number of adults with different types of neuromuscular conditions across Ireland. Her project started in Jan 2012 and she hopes to generate a detailed register and help develop specific care programs for individuals with the prevalence currently estimated at around 1/1500. A key point emphasised by Dr Lefter was that rare disorders ‘are not so rare after all’.

**Dr Amy Jayne McKnight** discussed some of the recent developments in Northern Ireland. Multiple surveys (e.g. National Patient Survey, McCollum report, Patient and Client Council reports) over the past few years provided data / information that they have been using to campaign for improved services in Northern Ireland. Issues include limited access to diagnostic testing, years waiting between specialist appointments, less than ½ patients do not receive required physiotherapy, and access to specialist equipment is variable. In the past few years the council have successfully campaigned for a paediatric neurologist and paediatric nurse specialist with a care advisor and MDC outreach worker hopefully joining the NI team in the near future. The most consistent message from patients, families and healthcare professionals in Northern Ireland is that more information is needed around neuromuscular conditions, so there has been a multidisciplinary effort to develop a patient journey and online portal for information.
Ms Helen Kerr talked about the latest findings on transition from childhood to adult services. Young persons and their family often develop close bonds with the paediatric team, but then feel as though they ‘fall off a cliff’ with a lack of continuity of care. It is known that good transition programs improve outcomes and Helen is starting a local project with 7 participants from NI and 7 from Dublin looking at how transition affects individuals with life limiting conditions. A structured transition program that starts early (10-14 years), improved self-management skills, collaborative working (joint paediatric and adult clinics) and an identified key worker all help improve patient outcomes through transition.

An excellent lunch was enjoyed by all and the afternoon focused on a series of Afternoon workshops discussing (1) adult physiotherapy (respiratory and neuromuscular), (2) paediatric physiotherapy, (3) adult nutrition and (4) paediatric nutrition.

The Physiotherapy workshops were hosted by Siobhan Macauley, Neuromuscular Physiotherapist, Belfast City Hospital and Claire Egan, Respiratory Physiotherapist, Beaumont Hospital, Dublin.

The Nutrition workshops were held by Barbara Shinners, Senior dietician, Central Remedial Clinic, Dublin. All workshop facilitators were very engaging and patiently stayed answering questions long past the time we expected workshops to finish!

After a short round-up Chairperson of MDI Elaine McDonnell closed the day by wishing everyone a safe trip home and said we were looking forward to going North for next year’s event!
We would once again like to thank our wonderful speakers who took time out of their busy schedules to present on the day. We would also like to thank the staff at City North Hotel for their excellent service, the exhibitors on the day Cooley Healthcare and S&E caretrade, Genzyme and most of all the attendees on the day who made the day such a success.

If you would like to access any of the presentations made on the day please email info@mdi.ie or call 01 6236414.