

## NEWSLETTER

*Message from Stephen Thompson, Chairman.***Welcome to the latest newsletter  
from the Northern Ireland Branch of  
Motor Neurone Disease Association.**

Sorry it has been so long since the last edition but we have been very busy and somehow the time slipped by. Never the less, since I last wrote an introduction, many individuals and groups have held fund raising events on your behalf and a lot of work has gone on behind the scenes to ensure people with MND are not forgotten in the changes to health care provision. We have also become involved in the Rare Disease Partnership that will also increase our voice in Government circles.

It is all very well to be active in these political fields but we need to ensure that we are providing the right services to you, the person living with MND. One of the major difficulties we have is that, while you are known to the Care Centre Staff patient confidentiality prevents us from accessing this information, we only know those who have joined the association and we would encourage you to do so as membership is free for those living with MND and their carers so we would love to hear from you.

We have included a few questions overleaf to give us a guide to what you would like us as an association to do and hope you will take time to send us your responses.

**How to become a  
member**

You can join online at [www.mndassociation.org](http://www.mndassociation.org) just follow the link **Become a member** or contact our branch secretary for an application form on 07561361556 or by email [marie@mndani.com](mailto:marie@mndani.com). Remember there is no membership charge for people living with MND and their carers.



**The Misfits** took part in the Belfast Marathon relay. Kim Walsh, whose younger sister has been diagnosed with MND, organized the team.

## FUND RAISERS ON THE RUN!

- **Norman Mulholland** also took part in the Belfast Marathon in memory of his good friend Graeme Diamond.
- **Paul McMullan** took part in the London Marathon in memory of his step mum Elsie.
- **The Carroll family** in Newry are taking part in the Newry Fun run.
- **Jonathan Bingham** is taking part in the Belfast to Dublin Maracycle in memory of Moore Brand.
- **Rick and Graham McGuinness** are planning to take part in the Andean Trail to Machu Picchu in memory of their mum, Nuala.

This is only a small selection of the many fund raising activities that people have organized to raise funds to help people living with MND. The Northern Ireland Branch Committee would like to say a huge **THANK YOU** to everyone for their efforts.

## We need your help

We are regularly asked if we run local support groups and this is something that we would like to develop but we need your help. We need information as to what services you would like us to try to provide, and then we look at your proposals and see what we can do. So please take a few minutes to answer the questions.

Thank you.

## Questionnaire

1. Are you
  - a. a person living with MND
  - b. A carer?
  - c. Other, please specify.
2. Would you like to attend a local group within 15-20 miles of your home?
3. Would you prefer an afternoon or evening meeting?
4. What sort of venue would you think was suitable e.g. hotel, garden centre, etc.?
5. What type of meeting would you like e.g. just to meet and chat?
6. Would you be able to help in the organisation of such an event?
7. What are your contact details?

**Email** [mndani@hotmail.co.uk](mailto:mndani@hotmail.co.uk)

**Text** 07711967990

**Fax** 02893323014

**Post** Stephen Thompson, 14 Seskin Road, Ballyclare. BT39 9NG



**Ross McDonagh** completed the 8<sup>th</sup> Elbaman Ironman Distance Triathlon last year and shared his sponsorship between MNDANI and Cancer Focus.

## MND Association AGM and Annual Conference

**7 September 2013  
at  
Radisson Blu,  
Stansted Airport.**

- The AGM will take place in the morning and in the afternoon Professor Kevin Talbort from the Oxford MND Care Centre will speak about the latest developments in research.
- People living with MND and one carer are able to attend the event without charge.
- Contact the Northern Ireland branch for more details.



Delegates Tony Carroll, Dorothy Steenson, Charlie and Paul Malone enjoying the AGM and Annual Conference last year.



NORTHERN IRELAND  
**RARE DISEASE  
PARTNERSHIP**

*Advocating, educating, and innovating for those living or working with rare diseases in NI.*

In March 2011, a group of organisations representing people with various rare diseases, representatives of the Northern Ireland Regional Medical Genetics Service, Rare Disease UK (RDUK), and individuals living with rare conditions got together, to see if there was sufficient common ground, need, and benefit in working together.

The Patient Client Council supported this initiative; and worked actively and supportively with us. DHSSPS also contributed to this initial thinking

*The NIRPD was formally launched on Rare Disease Day  
29/02/12.*

### **Aims**

#### **STRONGER TOGETHER**

**Advocating: Establish a networking/lobbying/policy Task-force, to**

- develop the Rare Disease Plan,
- ensure rare disease issues are mainstreamed into policies and programmes, and
- raise individual issues with relevant authorities

**Educating: Developing educational and training interventions to**

- improve awareness of rare diseases and rare disease issues and impacts, and
- increase levels of knowledge and expertise among medical and health and social care professionals

**Innovating: Work together to:**

- develop and implement improved methods of managing and treating rare diseases
- improve the quality of life for those affected by rare diseases; and
- increase the efficiency and effectiveness of care and support

**Working with and for people affected by a rare disease, their dependents, carers, and those treating them.**

Website [www.nirdp.org.uk](http://www.nirdp.org.uk) twitter @nirdpnews

The Northern Ireland Branch is funding a research post at RVH and Briege McLaughlin was recently appointed to the post.



Hi, my name is Briege McLaughlin and I have recently started a new post as MND research nurse within the Belfast Health and Social Care Trust. My role at present will involve researching ways of improving symptom management in people diagnosed with MND. I am also currently looking at research that has been carried out that looked at how families and carers cope with the diagnosis and the progression of the illness. I will keep everyone informed as my projects progress.

### Northern Ireland Branch Annual General Meeting

The AGM was held on 10<sup>th</sup> April 2013 in the Island Centre, Lisburn and was well attended.

The following office bearers were appointed:

- |                       |  |
|-----------------------|--|
| <b>Chairperson:</b>   | Stephen Thompson                                     |
| <b>Branch Contact</b> | Margaret McElfratrick                                |
| <b>Secretary:</b>     | Marie Holmes   |
| <b>Treasurer:</b>     | Hugh Groves  |
| <b>Webmaster:</b>     | Arthur Newell  |
| <b>Committee:</b>     | Tony Carroll,<br>Fiona Hutchinson<br>Siobhan Rooney. |

Following the election of Officers, Dr. Gavin McDonnell gave a very interesting talk about the new Neurology Centre at Musgrave Park Hospital, Belfast.

### NORTHERN IRELAND BRANCH

#### OFFICE BEARERS



Above left to right  
Margaret McElfratrick, Marie Holmes,  
Stephen Thompson and Hugh Groves.

*This is your newsletter so please let us have your contributions. These can be about fundraising, personal experiences, photographs of events and any other information that you think might be of interest to our members.*

**Email** [mndani@hotmail.co.uk](mailto:mndani@hotmail.co.uk)