



# NEWSLETTER

## From Past to Present

The MND Association was formed in Northampton in 1979 by a group of volunteers with experience of living with or caring for someone with MND. The Association's National Office for England, Wales and NI is based there at David Niven House. The Northern Ireland Branch of the Association was started by Barbara McCaughey in 1981. In 1986 the Branch asked National Office to appoint a Patient Care Officer for Northern Ireland. At this time the Association was very small and only had 2 or 3 people in that role working in England but they agreed and Margaret McElfrick was appointed to that part time post in NI. The role was to offer information, advice and support to people with MND and their families and to offer support and education to health and social care professionals working with people with MND but without previous experience or knowledge of the illness.

After Margaret retired from this role she became involved with the NI Branch as a volunteer and over the years has carried out the duties of Chairman, Secretary, Treasurer and in recent years Branch Contact. Over the years many people in NI have come to know her and her great knowledge has been appreciated by the branch committee. However, she has now decided to take a break from the Branch Committee after 18 years but is still a very willing volunteer when required. Siobhan Rooney has now taken over the role of Branch Contact.




(from left) Fiona Hutchinson, Helen McClean, Sally Light, Stephen Thompson, Margaret McElfrick. Photograph provided by Ulster Tatler.

In 1998 Helen McClean was appointed as Regional Care Development Adviser (RCDA), as the role is now called, and she retired at the end of March. The Regional Care Development Advisor (RCDA) is employed by the MND Association and works closely with the Northern Ireland MND Care Network. Over the past 18 years Helen has worked tirelessly to support people living with MND and their families, working closely with many partner organisations such as Ability Matters and the Communication Advice Centre, providing training for health professionals and supporting the NI Branch at a time when

the committee had been reduced to only 3 or 4 members. She has also seen the number of Association Visitors increase and now we have eight. Most recently she was also involved in the development of our Afternoon Tea support meetings. Helen leaves with our deepest gratitude and good wishes for her retirement and are delighted to welcome Crea Convery who has been appointed as our new RCDA. (Meet Crea on page 2).

## A Message from Our Chairman



Welcome to the latest edition of the MNDANI Newsletter. Since the last edition, our wonderful fundraisers have been very busy taking part in a whole range of activities running marathons, climbing mountains, skydiving, holding coffee mornings, taking part in charity football matches etc. Also this year several Golf Clubs have chosen us as their charity and we look forward to visiting them during the year. Our Afternoon Teas for people living with MND and their family/carers are well attended and there is a new group for past carers which meets at *Dobbies Garden Centre*, Lisburn. You will find details of these support meetings on our website. Let us know if you would like us to hold a similar event near you. I hope you saw the great article in Belfast Telegraph on 21<sup>st</sup> June when two of our members shared their MND stories for MND Global Awareness Day. Our AGM photographs were featured in the July edition of *Ulster Tatler*. *Stephen Thompson*

**Disability Exhibition**

This is held every second year around June and it is a great chance to see some of the available disability products, try them out and decide if they are suitable. It also gives you contact details for local companies that may be able to provide the products you need. A wide range of aids for driving or being driven was available, from hand controls to hoists, some are quite reasonably priced (most are not), some very sensible, some unsuitable (for me) but they may suit you. You should talk to a health professional about the suitability of any product for your needs but the exhibition allows a different perspective on the products and comparison with a number of similar products. Well worth a visit around June 2018. To the right are three interesting ideas, convert your manual chair to a three wheel powered chair, a two wheeled chair based on a Segway and load your chair (and you) into the boxer, then let someone cycle whilst you enjoy the view.



**Information Update**

**Care Information update**

The following Information sheets have been revised:

- 12C travel and Transport
- 12D Planning a holiday

You can download information sheets from our website. Click on 'Our information sheets' at [www.mndassociation.org/publications](http://www.mndassociation.org/publications). For hard copies of information sheets, contact our Care Admin Team: 01604 611812 or email [careadmin@mndassociation.org](mailto:careadmin@mndassociation.org)

**Research Info Sheets**

Did you know the research development team produce information sheets on topics including unproven treatments and clinical trials? Three recently updated sheets include:

- Inherited MND and Genetic testing (sheet B part 1 & 2)
- Stem cells and MND (Sheet F)

You can download them from the website [www.mndassociation.org/researchsheets](http://www.mndassociation.org/researchsheets)



**New Branch Contact: Siobhan Rooney**

Siobhan has taken over the role of Branch Contact and is available to offer a named contact service for individuals seeking help or information about MND, the Association or the Northern Ireland Branch activities.

This role involves:

- responding to telephone enquiries from the whole range of individuals in particular people with MND, carers and health and social care professionals;
- providing information on MND, the Association, Northern Ireland branch activities and local services;
- signposting individuals onto appropriate alternative sources of help, advice and information;
- attending Northern Ireland branch/support meetings on a regular basis.

She has been involved with the MND Association and is a member of the Northern Ireland Branch Committee since 2010. She is also a trained Motor Neurone Disease Association Visitor.

Contact Siobhan on 07434839842 or email: [siobhan@mndani.com](mailto:siobhan@mndani.com).

**Meet Crea**



My name is Crea Convery and I am pleased to be taking up employment with the Motor Neurone

Disease Association as the Regional Care Development Advisor (RCDA) for Northern Ireland. I worked previously as a Speech and Language Therapist in the Belfast Trust. I was a lead clinician in Stroke working in the Community Stroke Team for 24 years.

I am looking forward to working closely with the Branch and the MND Care Network and working on behalf of all of you who are affected by MND across Northern Ireland. As I settle into my role, I hope I will become a familiar face/name to you all.

On a personal note, I live in the countryside near Magherafelt with my husband Sean and little daughter Grace.

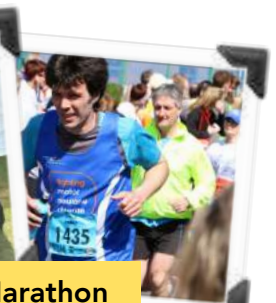


**Four Peaks Challenge**

A group from Armagh climbed the four highest peaks in Ireland in a 72 hour period and raised over £17,000 for the NI Branch.



**Belfast Marathon**



**Lurgan Musical Society**



**Annalong Football Match**



*Say 'Cheese'.*

**PHOTO GALLERY**



**Lisburn Marathon runner Piotr Sidor**



**Quinn Golf Day**



**Banbridge High School Presentation\***



**Antrim Rovers Charity BBQ in memory of Keith Rogers**



**Anne Thompson's Coffee Morning**



**Women's League Non-Subscribing Presbyterian Church**



**Paul Carlin and Michael Quigley who ran the London Marathon**



**Deborah Fitzsimon's 18th birthday sky dive**

\* Photograph supplied by Richard Hodgett, *Banbridge Chronicle*

**MND Connect**

Our MND Connect helpline offers advice, practical and emotional support and signposting to other organisations. Open Monday to Friday 9am to 5pm and 7pm to 10.30pm.

**mndconnect**  
**0808 8026262**  
[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)



**Ask Arthur...**

**Disability Action Transport Scheme (DATS)**

DATS is a local urban transport service for people with disabilities or for those who find it difficult using mainstream public transport. Membership is free but a fare is charged for each trip taken.

DATS is available in 29 urban areas across Northern Ireland. It can allow you to get about the operational area of the town you live in for whatever reason you may have including - going to work, shopping, visiting and attending health related appointments.

As a new member of the Transport service, you can book your first single or return trip within your operational area for free. After that, all single trips within your operational area are charged at £2.30 per trip.

See [www.disabilityaction.org/transport](http://www.disabilityaction.org/transport) for more details.



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)

**THE MOTOR NEURONE DISEASE ASSOCIATION**  
invites you to the  
**AGM and Conference**  
to be held at  
Radisson Blu Hotel, East Midlands Airport  
on  
**Saturday 10<sup>th</sup> September 2016**  
If you are interested in attending please contact our secretary,  
Marie Holmes, for more information at  
[marie@mndani.com](mailto:marie@mndani.com) or phone 07561 361556



**Contact us...**

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**Join the MNDA Family**  
Many people have supported us over the years by fundraising, so why not become a member and you will find out more about the MNDA Association and the work they do for people living with MND?  
**Become a member**  
You can join online at [www.mndassociation.org/membership](http://www.mndassociation.org/membership) or contact our branch secretary, Marie Holmes, for an application form on 07561361556 or email [marie@mndani.com](mailto:marie@mndani.com)  
Remember membership is **free** for people living with MND and their carers.



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