

NEWSLETTER

SKY'S THE LIMIT

From abseiling down the Obel Tower, Northern Ireland's highest building, to a sponsored walk, Edel Fearon (*fourth from the left*) has raised over a thousand pounds for the Northern Ireland branch of the MND, in memory of her father and here she tells the branch newsletter why she is determined to raise even more.



Newry girl, Edel (29), and her entire family were devastated when they were told that their father Frank had motor neurone disease. Edel, "It was around August last year that we got the tragic news of my dad's condition – he had motor neurone disease. Sadly Edel's father passed away in February this year after battling MND for eight months, although Frank's family believe he had the illness for a much longer time. Since then, aware of how vital funds are for the Association, Edel's family and friends have embarked on an epic fundraising venture in Frank's memory.

As well as hosting a quiz night, scaling the Obel Tower in Belfast and participating in a sponsored walk up Slieve Donard, Edel plus family and friends are already looking ahead to 2014.

Edel says: ***"My plans are now for a skydive which will hopefully happen in March or April next year. I'm also planning a balloon release day – which will help commemorate those who have died of motor neurone disease and I'm hoping to raise money through that too."***

**Message from our Chairman,
Stephen Thompson.**

It seems like no time since I last wrote a message for our newsletter but like all good things it has come round again. It has been a busy summer in the world of the MND Association, the generous people of Northern Ireland have been successfully fund raising, all sorts of things have been happening; cycling tours, sports events, sheepdog trials, BBQs and much more.

We are eternally grateful to all fundraisers without whom we could not supply the services we do.

It is the intention of the Branch to maintain and grow services for all people with MND, but we do need your input. In our last newsletter we asked you to return a questionnaire giving us some idea as to your wider needs, to be frank we were disappointed with the response. You may feel that your needs are different to others but you may be surprised just how many of these needs are common to others. The survey is on the website www.mndani.com/survey.asp so have a look at it and you will also see some of the fundraising events I mentioned earlier. *Thank you.*



SOME FUNDRAISING EVENTS

- Ian Steenson, his son, 13 year old son Thomas, and colleagues took part in the 85 mile Lap the Lough cycling event in memory of his father Ivan.



- Lambeg Golf Club's Lady Captain's charity day supported MNDANI.
- Castlerock outdoor bowlers held a BBQ.



- Ards Cycling Club organized a cycle tour of Strangford Lough and 100 cyclists completed the 60 miles in poor weather conditions.
- South Tyrone Unionist Party organized a BBQ.



Helen McClean is the RCDA (Regional Development Care Advisor) for NI.

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I joined the Association over 15 years ago from a background in the Health Service and cover the whole of Northern Ireland.

One of our aims is to promote and secure the highest possible standards of care for people living with MND and their carers. This can be achieved through raising awareness of your needs among health care professionals, not only on a one-to-one basis but also by offering educational opportunities. Being aware of your needs allows me to champion them with service providers and through joint initiatives i.e. the Northern Ireland Rare Disease Partnership (NIRDP).

ASK ARTHUR

Contacting 999

It is not possible to send a text message to 999. To get round this problem, the PSNI has created a number specifically for text messages which will assist people with hearing or speech difficulties to contact the police in an emergency. You must preregister before you can use this service, see

http://www.psni.police.uk/index/support/emergency_sms_text_service.htm

for more details. If your request is for the Fire and Ambulance services then it will be passed onto them.

Contacting the RAC

Many of you will be Motability customers with breakdowns covered by the RAC. If you prefer you can text your breakdown details to the RAC using **07855 828282** rather than phoning them.

Power NI

If you are dependent on electrical equipment for healthcare you should join NIE's Critical Care Register. Telephone **08457 643 643** for more information.



Arthur Newell chatting with a member of MND staff at AGM & Conference.

MND Association AGM and Annual Conference 7 September 2013 at Radisson Blu, Stansted Airport

This year three members of the Northern Branch Committee attended the AGM and Conference. The weekend started on the Friday evening with a very enjoyable informal buffet where there was the opportunity to chat, renew friendships and make new contacts. The NI party met Sally Light, the new Chief Executive, Stephen Bell, Director of Care (North) and a new Trustee Helena Marsh and her husband. Helena's sister, Kim Walsh, is a member of the Northern Ireland Branch and she had also travelled over to attend the AGM and Conference.

After the AGM the following morning, we attended the Volunteers Focus Group that was led by Sally Light, Chief Executive. This was very helpful as delegates had the opportunity to give their opinion on the Association's plan for the next three years. The plan is 'How to best focus our efforts to support everyone affected by MND, and achieve our vision'.

In the afternoon we attended the Annual Conference where the keynote speaker was Kevin Talbot who is Professor of Motor Neuron Biology at the University of Oxford in the Nuffield Department of Clinical Neurosciences. He gave a very interesting talk on the research that was taking place to improve our understanding of what triggers motor neuron degeneration.

Both sessions are available at <http://new.livestream.com/eventstreamingcompany/mnda>



Castlerock Sheepdog Society supported MNDANI at their Annual Trials.

Looking for a Loo?



Many accessible toilets are locked to stop vandalism and antisocial behaviour. If you need to use them, finding someone with a key may be difficult – often you are in a hurry and need a key NOW.

One key will unlock most accessible toilets; the key is available from the Royal Association for Disability Rights (RADAR) and costs £4 including P&P.

You can phone Radar on 020 7250 3222 or send an e-mail to radar@radar.org.uk or order online from <http://www.radar-shop.org.uk/>



The Northern Ireland branch will be trialing an online chat room **each Wednesday from the 8th to the 29th January 2014 between 8 and 9pm.**

It will be open to those living with MND, carers, family and friends discussing whatever you wish so why not join us. It is an informal chat between friends and you may remain anonymous. Look at www.mndani.com/chat.php for more information and to confirm your PC is suitable.



Left to right:
 Back: Fiona Hutchinson, Eleanor Smyth, Siobhan Rooney and Marie Holmes.
 Front: Amanda McMullan and Anne Sleith.

Meet your Association Visitors (AVs)

Association Visitors perform a vital role in supporting people affected by MND by providing confidential emotional support, information about the Association and other services.

The majority of our current AVs are people who have been personally affected by MND or who have been health or social care professionals.

AVs will have attended a comprehensive training course provided by MNDA.

In NI we now have six AVs and anyone affected by MND can request a visit through Helen McClean our RDCA

08453751852

helen.mcclean@mndassociation.org

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

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How to become a member

You can join online at 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 Remember there is no membership charge for people living with MND and their carers.

mndconnect
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