



**MOTOR NEURONE DISEASE ASSOCIATION NORTHERN IRELAND BRANCH NEWLETTER**

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A warm welcome to you all again. Following on from the first newsletter please find the following updates.

**Celebrating the Care Centre @ Stormont**

On Monday 14 April the work of the Northern Ireland MND Care Centre was celebrated at a special event held at Stormont, seat of the Northern Ireland Assembly in Belfast. The Northern Ireland MND Care Centre was set up four years ago with a grant from the MND Association to the Royal Victoria Hospital in Belfast. Usually Care Centres provide a clinic setting at one hospital where people can see all the professionals they need during one appointment. However, the Northern Ireland Care Centre differs from the traditional model in that care is delivered and managed as geographically close to the person as possible, making the Care Centre a virtual centre.

The aim of the event, hosted by Carmel Hanna MLA, was to celebrate the work of the Northern Ireland MND Care Network, and the positive difference it makes to the lives with people with MND and their families. Alan Graham, Chairman of the MND Association welcomed everyone to the celebration and was followed by Chief Executive Kristine Knox who talked about the need for continued funding of the Care Centre. Tricia Holmes, Director of Care Development announced the decision to rename the Care Centre to Care Network, in order to reflect the virtual nature of the model.

Many of those involved in the setting up and continued development of the network attended the event. Guests included Lady Halifax who led an appeal to raise funding for six Care Centres; Lady Halifax's brother Mr Blakiston-Houston, who made a significant contribution to setting up the Northern Ireland Care Centre; and surprise guest Michael McBride, Chief Medical Officer for Northern Ireland.

The Northern Ireland Branch of the MND Association were closely involved in the event and made a special presentation to Dr Victor Patterson, the MND Care Network Director who is due to retire at the end of May. The MND Care Network provides a vital service for the 95 people living with MND in Northern Ireland.

**The Caring Caretaker doing what he does best.**

The Branch is very happy to be linked with Mr. Davy Boyle from Coleraine for 2008. Since the last newsletter Davy has been out doing what he does best and has completed the following collections

- 15th March Sit Out Collection at Tesco Coleraine.
- 20th March Bag pack in Tesco Ballymoney.
- 24th March Sit Out Collection at B+Q Coleraine.

**And the biggest event year to date - 3rd May Jail and Bail.**

Davy was able to round up 13 local faces in the Coleraine / Northwest Area, including the new mayor of Coleraine. At 10.00am on Saturday morning they were arrested at Coleraine Town Hall and marched around the Diamond by the local PSNI. Dressed in their white scrubs they were then rounded up and placed in the back of the local Paddy Wagon where a fee of £500.00 or over was required to bail them out. The event was a huge success for Davy but only lasted approx an hour. The reason, well Coleraine don't make it to the Irish Cup Final that often so Mr. Boyle was on the way to Windsor Park to cheer on the boys. Next Newsletter we will have an interview and Q&A session from the Great Man himself.

**Getting to know your MOTOR NEURONE DISEASE ASSOCIATION NORTHERN IRELAND BRANCH?**

**Stephen Thompson**

1. **How did you first come into contact with MND?**  
My wife suffered from MND in 1996/97

**2. When did you become a member of the Branch?**

In 1997 after her death.

**3. What does your current role involve?**

Coordination of branch activities ensuring support is given to all patients who require it and ensuring the funds are in place to do so.

**4. What the best thing about your role and the MND Branch?**

The most gratifying thing about involvement is seeing the amazing resilience shown by those with MND and their positive outlook.

We are always in need of help, and you may feel you can do something however small to help us, there are lots of ways.

1. Join the Association, if you are a person with MND it is free, otherwise the cost is an annual fee of £12.
2. Have one of our collecting boxes for your loose change or better still ask your friends, local shop, workplace, pub or wherever to take one, if you want one Ring Darren on 07871957278.
3. Support a fund raising event in your area, we have shown some later in this newsletter. Or better still run an event yourselves, it doesn't have to be big, a coffee morning, sponsored walk anything.

We are here to help and advise, get you T shirts etc. Ring the branch helpline - 02893342040.

### Details of Remaining 2008 Events

Davy Boyle

- 7th June Tesco Ballymoney 9-6.
- 28th June Sainsburys Coleraine 8-6.
- 26th July Asda Coleraine 9- 6.
- 25th September Railway Arms Pub Quiz - details TBC.
- 27th September sponsored walk - Coleraine to Portrush and Portstewart and back.
- 3rd Oct Concert in the Town Hall by the 7 Towers Choir - £6 per ticket, hall holds 360.
- 8th - 24th December Sit out - Coleraine Town Centre

### Committee Member Darren Cheevers does his bit for the Fight against MND

Since the last Newsletter along with 4 friends, I took part in the Belfast Marathon Relay. We came home in a time of 3hrs 54min 16secs. Overall we finished a very respectable 401<sup>st</sup> out of 1637 teams. It was great to see a lot of people running with the MND vests and T-shirts on and even the guys in the team who weren't not fully aware of MND were surprised by the number of people commenting on the good cause they were running for.

So a heartfelt mention and thanks to all runners, walkers, young and old for taking part in the Belfast Marathon and raising money for MND, see you all next year!!! My personal thanks to Paul, Neville, Nigel, Jason, Joanne, KT and Helen.

New and Remaining events are:

1. Lisburn 10k - 18<sup>th</sup> June
2. Ballyronan Triathlon - 16<sup>th</sup> August
3. Sponsored Cycle London to the champagne district, Reims - September
4. There is a slim chance the Dublin Half Marathon may be attempted...watch this space!!!!

### Committee Member John Hurson and the WALK to D'feet MND

Saturday 21 June is the date set for our "Walk to D'feet MND". This year, the location is Stormont, where we will walk from the gates to the steps of Stormont Parliament. This will take place at 3pm. This popular event will be an easy and enjoyable way for anyone to play a part in raising funds and awareness towards taking a step closer to realising our vision - A World Free of MND!

For further info or to receive a sponsorship form, contact: John Hurson on (028) 8772 9997 or 07875396335, Darren Cheevers on 07871957278 or Stephen Thompson on (028) 9334 2040

We will be joined on the walk by our branch Patrons, Conor Grimes and Alan McKee, stars of the BBC 1 "Tractor Show". Each registered walker will receive a Walk to D'feet T shirt and a certificate on the day. So dust off the walking shoes and join us for a fantastic event.