

Latest In Raising Awareness

It has been a busy few months for the branch as a number of high-profile events have taken place right across Northern Ireland to raise awareness and funds for MND.

In June, the lights at Belfast City Hall were illuminated in the MND Association's distinctive colours of blue and orange for global MND awareness day.

Several people living with MND as well as their family and friends attended the event at the front of Belfast City Hall, which was also attended by the Lord Mayor of Belfast, Nichola Mallon.

Also in June, motorcyclist Mark Bowers made a stop-off at the RVH Care Centre in Belfast during his tour of the UK where he visited all of the MND care centres.

Our volunteers and branch members took part in this summer's inaugural Disability Pride event in Belfast when hundreds of people took part in a parade in the city centre in a mass celebration.



Top of the Class

Connie, Lauryn, Maya, Lexi & Leah from Bloomfield Collegiate School raised awareness of MND by choosing MND Association for their presentation as part of the Youth and Philanthropy project in their school.

Staff and pupils at St Colman's Primary School, Annaclone, Banbridge raised over £1000 for the NI Branch.

At 

ICE BUCKET CHALLENGE

Throughout the summer the global ice bucket challenge reached Northern Ireland shores and people here were more than willing to take up the quirky challenge to raise funds for MND research.

Donations flooded into the branch's new Just Giving site as people of all ages dumped icy water over their heads following in the footsteps of ALS supporters in the US, where the craze first emerged.

Celebrities, sport stars and local politicians even got in on the act. Our patrons, comedians Grimes and McKee, soaked Belfast Lord Mayor Nichola Mallon in the grounds of City Hall.



MESSAGE FROM OUR CHAIRMAN

Welcome to the latest edition of the MNDANI Newsletter, I hope you are getting some benefit from the information we send you. This edition will tell you some of the things that have happened since the last edition. In May we were invited by the Seekers to hold a bucket collection at the Waterfront Hall and later that month the Chief Executive, Sally Light, visited NI and met with the Branch Committee and Association Visitors.

As usual there have been too many events to list them all, most were fundraising events and as always we are very grateful for those efforts but some were designed to help awareness of the disease most notable of these was Disability Pride Day in Belfast which was a great success.

You have probably seen all the publicity around the Ice Bucket Challenge and maybe you have taken part in it.

The challenge has been a runaway success and this windfall has allowed additional funding to go to research and the Association has been able to bring forward some programmes scheduled for the future. In addition there will be a new scheme for families more details about this will be announced soon.

As always we want your feedback on anything concerning MND, no matter what, as it allows us to improve our service to you so do not be shy to contact MNDA NI.

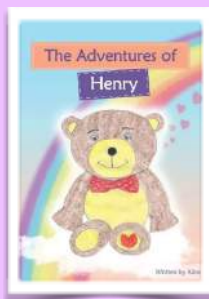
Stephen Thompson, Chairman

THE ADVENTURES OF HENRY

When Alice Chambers, who had MND, had to go into hospital to have a feeding tube fitted her friend Ma White brought her a bear called Henry. However, when Alice returned home from hospital the bear was lost!

If you are interested in buying this delightful children's story, email henrytheadventurebear@gmail.com for more details.

The book costs £3.50 all of which is being donated to the MND Association plus postage and packaging.



ASK ARTHUR

As we approach winter there are a few things that can ease the burden of the long winter months:

- **Flu Vaccination** – If you are a person with MND or their carer then why risk the flu. Most GPs will have contacted those at risk by now, if you have not been contacted then phone your GP.
- **NIE Critical Care Register** - If you are dependent on electrical equipment for healthcare you should join NIE's Critical Care Register. Telephone **08457 643 643** for more information.
- **NI Water Customer Care Register** – If you have a serious medical condition or need extra help for any other reason. You need to join the NI Water Customer Care Register to get the extra free services you or anyone in your household would like to receive. See <http://www.niwater.com/customer-care-register/> for more details.

GOLFING MATTERS

We are very grateful to NI Golf Clubs who have supported MNDA NI.

This Year City of Belfast Golf Club have chosen MNDA NI as their Charity of the Year.

In July Mamie and Brian McAllister sponsored a Golf competition at Cairndhu Golf Club to raise funds for MND Association. The Ladies Section, of which Mamie was a member for 33 years, organised the competition and ballot on the day. The following Thursday, Ladies Day, all the competition funds plus the proceeds of a ballot were generously donated to add to the amount raised on the previous Sunday. Over £1550 was donated to the charity.

Castlerock Golf Club supported MNDA NI on their President's Day and over £2000 was raised.



ANNUAL CONFERENCE and AGM

Eight of our members attended the Annual Conference and AGM on Saturday 13th September, which was held in the Radisson Blu Hotel, East Midlands Airport. As usual delegates travelled over on Friday afternoon and were therefore able to attend the buffet that evening. This is an opportunity for delegates to chat informally and discuss many issues including the amazing ice bucket challenge.

On Saturday our Chief Executive, Sally Light, opened the day by reflecting on the year gone by, and shared some highlights from the events she had attended and the stories of the people she had met. It was great to see the first picture on display was of Belfast Lord Mayor, Nichola Mallon, doing the Ice Bucket Challenge with our branch Patrons, Conor Grimes and Alan McKee! Delegates then had the opportunity to attend Learning Workshops on a range of topics - care, campaigning and raising awareness, volunteering and fundraising. After a lovely lunch the AGM took place chaired by outgoing Chair of the Trustees, Mark Todd. He was presented with a painting by Sarah Ezekiel who produces artwork using eye-gaze technology. The new chair of the Trustees, Alun Owen, spoke briefly to introduce himself and his personal connection to the disease.

Delegates listened to a presentation from Professor Ammar Ai-Chalabi, Consultant Neurologist at King's College Hospital and Director of the King's MND Care and Research Centre, entitled MND: Nature, nurture, risk and chance which explored the causes and development of MND.

The Annual Conference and AGM is a great opportunity to meet people living with MND, carers and other volunteers as well as viewing the exhibitions and information stands which allow you to find out more about a whole range of resources. Our own Michael Holden from Trip-Ability.com was among the exhibitors. We would encourage members to think about attending this event next year. The conference is available to watch at

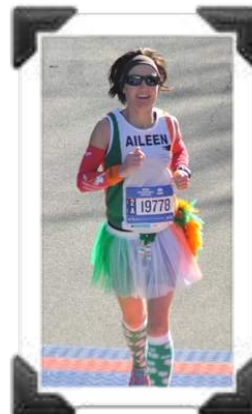
www.mndassociation.org/news-and-events/events/conferences/AGMandAnnualConference

Photo Gallery



Edel Fearon & friends who took part in a skydive.

Clonduff Vintage & Classic Club held a tractor run & fun day.



Aileen McSorley ran the New York Marathon.



Sean Weir Shaved off his 25 year old ponytail!

McAnerney's supermarket organised a sponsored walk and fun day.



Shane Lavery ran the Belfast marathon.



Chris Eastwood, owner of Dunleath Bar in Cookstown, organised a dart competition.

Ballynahinch Motor held a BBQ at Carryduff Forklifts.



A Royal Afternoon

In October three of our AVs, Amanda, Fiona & Marie, attended the annual AV Forum which this year was held in Stratford upon Avon. This is an opportunity for AVs from England, Wales and NI to meet to discuss issues affecting people living with MND, their families and carers.

During the afternoon session HRH The Princess Royal, MND Association Royal Patron, joined the AVs for the round table discussions that were focusing on supporting young carers.

Our team of Association Visitors has now increased to seven as John Fogden from Londonderry/Derry has now completed his training.

If you would like an AV visit please contact Helen McClean, NI Regional Care Development Adviser, on 08453 751852.



Information Sheets

10 Swallowing difficulties

11 PEG & alternative feeding



Both these sheets have been endorsed by the British Dietetic Association (BDA) and can be downloaded at www.mndassociation.org/publications or you can order them by ringing 01604 611812 or email careadmin@mndassociation.org

If you would like to talk to someone about MND please contact MNDConnect on 08457 626262 or email the MND Connect team on mndconnect@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.

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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 **07561 361556**

or by email marie@mndani.com

Remember there is no membership charge for people living with MND and their carers.

The views expressed in this newsletter are not necessarily those of the MND Association.

The products and services mentioned or promoted should not be taken as recommendations by the Association, who cannot be held responsible should any complaint arise.

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