



NORTHERN IRELAND MASCOTS MEET WORLD'S BIGGEST TENNIS STARS!



In November 2013 several children from families affected by MND had the opportunity to be mascots at the Barclays ATP World Tour finals. The children met some of the world's biggest tennis stars, including Roger Federer, Novak Djokovic, Rafael Nadal and recent Australia Open winner Stanislas Wawrinka at the prestigious event held at London's O2 arena, after being nominated by members of the Motor Neurone Disease Association. The Association was invited to put names forward for the honour, following the death of Brad Drewett, a former player, executive chairman and president of the ATP World Tour who died from motor neurone disease (MND) in May 2013, aged 54.



From top: Eilish Larkin with Roger Federer, Noah Holden with Novak Djokovic Georgia Holden with Stanislas Wawrinka & Ava Finnegan with Juan Martin Del Potro.

A spokesperson for the Barclays 2013 ATP World Tour said: " Each day the mascots arrived with excitement and they have been true professionals. We hope it is something they and their families will remember; while also helping to honour Brad and, hopefully, raising the profile of the Motor Neurone Disease Association and their fight against this dreadful disease." The Northern Branch is very proud of their young ambassadors.



Message from our Chairman, Stephen Thompson.

Welcome to the latest edition of our Newsletter and I hope that you are finding it useful and informative. As the Northern Ireland Branch of the MNDa builds up its communication base with you all it is hoped that you will respond and help us offer better services to you all. As usual lots of individuals and groups have been fund raising on our behalf and we are eternally grateful for their efforts.

The Branch AGM is coming up soon again and we would love to see you there: don't worry you won't get a job unless you offer your services but we would like to hear your views so come along and have a cup of tea with us. *Thank you.*

NEWSLETTER

HAVING FUN FUNDRAISING!

Christmas themed Pony Parade in Ballycastle organized by Roisin McGinn



Malone Lodge Hotel, Belfast held a Family Fun Day in support of MNDA NI and Tiny Life.

Photo courtesy of Ulster Tatler



Newcastle swimmers held a sponsored swim in the sea on Christmas Day.



“Biggest Loser” weight loss competition



Campaign to reduce waiting times for diagnosis

The Association is currently campaigning to reduce the length of time people with suspected MND wait to have their diagnosis confirmed in Northern Ireland. The delays are being caused by long waits to see neurophysiologists; specialists who help neurologists confirm a suspected diagnosis by running tests (including nerve conduction studies and electromyography).

The official waiting time to see a neurophysiologist, as set by government, is nine weeks. However, more than half (63%) of people in Northern Ireland wait longer than nine weeks for their appointment. Length of time waited by people with suspected MND specifically are not collected or monitored by government, but we know from neurologists that people can wait months for their appointment. The Association has raised the problem in the Assembly and, thanks to the branch’s new Campaign Contact Jennifer Maloney, in the press. We are currently in conversation with Belfast Trust (where the vast majority of tests are carried out) about ways of fast tracking people with suspected MND.

Access to an early diagnosis is one of five statements in the MND Charter, which has been signed by the Health Minister and many Assembly Members. Early diagnosis is important because of the fast-paced nature of MND, and because it opens up access to essential health and social care services.

We will keep you up to date as the campaign develops.

What you can do:

- Spread the word about the campaign! In particular, we need to hear from people who waited a long time for their diagnosis to be confirmed. Please contact our Campaign Contact Jennifer Maloney if you are/ know someone this applies to (jennifer_maloney@hotmail.com).
- Join the MND Campaign Network so you receive regular updates about this and other campaigns. Sign up at www.mndcampaigns.org/campaign_network
- If you use Twitter, follow our dedicated campaigning account @mndcampaignsNI

**NORTHERN IRELAND BRANCH
of the
MOTOR NEURONE DISEASE
ASSOCIATION**

Invites you to the
ANNUAL GENERAL MEETING
which will be held on
Wednesday 26th March 2014
in the **Lagan Valley Island Centre, Lisburn**
at **7.30 p.m.**
GUEST SPEAKER: Briege McLaughlin
(MND Research Nurse at RVH)

MND
connect
08457 626262

If you would like to talk to someone
about MND please contact our MND
Connect team or email
mndconnect@mndassociation.org

**Arthur enjoying a
baseball game in
New York.**



Flying with a Wheelchair

You can fly with a wheelchair (either electric or manual) on many airlines but you need to contact the airline in advance; if you are using an electric wheelchair then allow more time for them to confirm you can travel. The airline will need specific details about your wheelchair so you may need to contact them several times before they have all the information they need.

Special Assistance are people who will help you right to your seat and you can even arrange for their help to start at the car park, check in or wherever suits you. Some airports are quite large and although you may have a family member willing to push you, why not save their energy until you are at your destination! Getting through airport security is one area where having Special Assistance helping is an asset. They know where to go and what the security screening needs, they make a stressful process much friendlier.

All airlines have a similar boarding process; you drive or are pushed up to the airplane door. You may be able to walk to your seat, if not you will transfer into an aisle chair. This is a very narrow chair that can fit in the space between the aircraft seats. The time consuming part is when they fasten lots of straps to secure you into it. Once all the straps have been fastened you are totally under their control! The Special Assistance people will then wheel you to your seat. If you cannot transfer then Special Assistance will lift you into your seat.

There may be steps to the aircraft; in this case an "Ambulift" is often used. This is a van that can lift you up to the aircraft door, with level access all the way. As you are being wheeled to your seat on the plane, keep your arms in as it hurts when you catch an arm on an aircraft seat and the aisle is very cramped. Many long haul flights carry an on board wheelchair which can be used to get you to the toilet, confirm before you travel if your flight has one. Short haul flights do not carry one.

You may have other specific requirements e.g. Oxygen, confirm these with the airline before you travel and note that there may be a charge. An airline will carry two mobility items free of charge but again confirm with the airline before you travel.

At your destination airport similar assistance will be supplied, this will get you to the airport taxi rank, coach or train station or car park. If you will require a wheelchair accessible taxi then most airports have these but you should book in advance.

Check out further travel advice on www.mndassociation.org

Ask Arthur.....

Let the train take the strain

Those of us who use a wheelchair feel confined to using our own vehicle or a taxi to get around. We overlook Translink as a possibility. I would take the train if at all possible, as it is so easy and relaxing. Modern trains are easy to board via a ramp, most of the larger stations have a ramp and all trains carry a ramp. Some smaller stations have limited wheelchair access but the Translink web site <http://www.translink.co.uk/accessibility/> identifies all station facilities, if you prefer you can ring **028 90 66 66 30** for details.

If you intend travelling on the Cross-border services then you must book in advance as these trains have two dedicated spaces for wheelchair users.

Some Bus and Coach services are wheelchair accessible but you must confirm this prior to travel.

As well as the 60 plus Smartpass, which entitles you to free travel if you are aged 60, or over, there is another Concession Pass, which allows you a 50% discount on all standard single fares.



ITCanHelp



Many people will have received a new gadget for Christmas; unfortunately it may be sitting in the box because they need a helping hand to get started.

AbilityNet's free helpline offers expert advice and information about how disabled people can use computers and the internet.

They have a home visit service (ITCanHelp) which has a network of AccessNI checked volunteers who offer free assistance to disabled people in their homes.

You can find out more from their website <http://www.itcanhelp.org.uk/>

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.

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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