

Newcastle Motor Neurone Disease Centre

Newsletter

Issue 96

January 2020



The MND register of England, Wales and Northern Ireland is the first comprehensive source of information collected by experts about people living with MND and you can play a vital role in its development.

Pioneered by MND specialists Professor Ammar Al-Chalabi of King's College London and Professor Kevin Talbot of Oxford University, the MND register aims to:

- Collect information about people living with MND, to understand more about why certain people are vulnerable to the disease.
- Find out precisely how many people currently have the disease and how this is changing over time.
- Established where people with MND live, to help improve care in those areas
- Collect detailed information about the disease to detect patterns of change in incidence and outcomes.

How to join the MND Register

You can apply online at www.ndregister.ac.uk or ask about joining when attending your next clinic appointment. If you have any questions please visit the website www.mndregister.ac.uk alternatively you can email mndregister@kcl.ac.uk or call Oxford 01865 227714 or KCL 0207 8485258



Seasonal flu Vaccinations

This year's seasonal flu immunisation programme is now underway and people living with MND should already have been contacted by their GP. Anyone who hasn't been contacted by now should contact their surgery as a matter of urgency.

If you are living with MND and would like more advice about getting seasonal flu jabs, visit or contact MND Connect on 08088026262; email mndconnect@mndassociation.org



Patient/Carer Drop-in Sessions

The Newcastle patient/carers support group runs on the first Friday of every the month at Marie Curie Hospice in Elswick. The times are 1:00pm – 3:30pm. It is a very informal group. It would be nice to see some new faces, so please come along for a chat and catch up with other patients and carers, enjoy light refreshments in a lovely relaxing setting, with a relaxing head & shoulder massages for anyone who wishes. One of the MND care co-ordinators or nurse specialists will be in attendance should you have a problem to discuss.

These sessions are for you. If you have any ideas on the format you would like them to take or specific speakers you would like us to arrange, please let us know and we will try to accommodate your suggestions. There will be no meeting in January, the first meeting is the 7th February 2020, (programme attached)





Durham & Darlington Support Group

The Durham & Darlington Support group is held on the second Thursday of each month at the Brambles Coffee Shop, Poplar Tree Garden Centre, Shincliffe, DH1 2NG from 2-4pm. For further information please contact Geoff & Wendy Sheldon on 07548107509 or email geoffsheldon6899@aol.com



Holiday Information Fact Sheet

Now that Christmas is over our thoughts turn to warmer times. Over time here at the Newcastle Motor Neurone Disease Centre we have been given the names and information of various holiday lets both in this country and abroad, who offer good accommodation for those who may have mobility difficulties. There is also a section on insurance companies who cater for people with pre-existing medical conditions. The information has been collated into a fact sheet. If you would like a copy please contact Marian at the MND Centre on (0191) 2823693, or email marian.dent@ncl.ac.uk

Also if there is somewhere that you have tried and enjoyed and would like to share it with others, we would be more than happy to include it on the fact sheet.





Sponsored Walk in Aid of Motor Neurone Disease

*WALK TO D'FEET is a Trademark of The ALS Association and is used with permission. All rights reserved

It's that time again to start thinking of our annual Walk to d'feet to raise money and awareness of motor neurone disease. So get your walking shoes out for Sunday 14th June 2020.

Again this will be from the Tyneside Riverside Country Park at Newburn along the Wylam Wagon Way to Wylam and back! It is a 5 mile walk, which is wheelchair and dog friendly. It is a very pleasant walk (even in the rain!) with no hills hiding around the corner! As we walk along the wagon way we pass George Stephenson's birth place. A small white stone railway cottage, which has been refurbished to reflect domestic living in 1781, the year Stephenson was born. The cottage also has another claim to fame as the National Trust's smallest property in Northumbria.

If you are interested in joining in please contact Marian at the MND Centre on (0191) 282 3693 or email marian.dent@hotmail.co.uk who can forward an information sheet and sponsorship form. All monies raise on the day will go to the local Branch of the Motor Neurone Disease Association.



MND Association Patient Forum

The MND Association have a patient forum on their website. This is a forum for people affected by motor neurone disease to share experiences and support each other with the challenges of living with the disease. The web address is:

<http://forum.mndassociation.org>