

Message from your Chairman



A very Happy New Year to all our readers from all of us and we do hope your Christmas turned out to be as enjoyable as you had anticipated. The dark nights are beginning to shorten and we look forward to 2017 being as successful for the Branch as 2016 turned out to be. The Christmas Lunch at the Millstones restaurant was a great event with much merriment and good food, culminating in our friends from DNH finding themselves broke and having to have a whip round - but it was so nice to have them with us!

Plans are ahead for a repeat of our Swing into Spring event (25th March) and our AGM in March when we are hoping to let you have a report on the research project we are now part-funding at SITraN. You may recall that we received an unexpected legacy from a friend from the past (Freddie Briggs), so the committee, having discussed the possible wishes that Freddie might have had, decided that a suitable research project would be the most appropriate. After consultation with Brian Dickie, a closely related project to the zebra fish project that the Branch had previously helped fund was chosen at Sheffield with Dr Tennore Ramesh, who presented his work at the Regional Conference in Leeds which some of you may well have heard.

We will be in attendance again at the Ripon Old Cars gathering at Ripon racecourse (although not as a beneficiary this year) and lunch social dates are detailed elsewhere plus the usual reminder for the tea meetings at Christians.

A final word: we really could do with a few new faces to support the Branch in all we do which is a most rewarding way in which to devote a few hours of your time to such a good cause. Please, as a belated New Year's resolution, think whether you could spare us a little of your time and if so contact one of us! Thanks – we'd be so grateful!

Peter Thompson

The Zebra Fish Project

Some years ago we allocated a considerable amount, spread over three years, to the Grierson Zebrafish project which began in 2011 and which is now showing hopeful results. This project involves the use of a zebrafish model of MND to efficiently screen over 2,000 potential drugs for any beneficial effects and also provides the researchers with opportunities to study and better understand how neuronal stress develops and spreads in MND, offering insight into the earliest stages of the disease. Zebrafish, like mice and humans, are vertebrates and many genes are similar in human and fish.

Dr Ramesh and colleagues have developed a zebrafish model of MND that incorporates a mutated form of the SOD1 gene. The researchers have already established that this model shows most aspects of MND seen in mice and humans, including muscle wastage, paralysis and premature death. When Dr Ramesh's team treated the mutant fish embryos with riluzole, a drug that is already used to treat MND, they saw a reduction in neuronal damage. This confirms that their fish model can be used to quickly demonstrate the effects of potential drugs and will allow them to use it for a relatively efficient large scale screening programme of 2000 drug compounds. Many of the compounds they will screen are already approved for human medicinal use and if any of these show promise, translation into human clinical trials could be developed in a relatively rapid time scale.

The work being conducted by Dr Tennor Ramesh is going well but £50,000 is still needed to complete the project. We therefore agreed to donate £20,000 to the project. If you would like to know more then please follow this link <https://www.sheffield.ac.uk/neuroscience/staff/ramesh> and this one <https://mndresearch.wordpress.com/2013/01/30/zebrafish-show-that-connector-neurons-are-the-key-in-early-stages-of-mnd/>

A Few Snippets from the National Website

Birthday Wishes: The Association would like wish our patron Professor Stephen Hawking a very happy 75th birthday. Chief Executive, Sally Light has these warm words: “Professor Hawking was diagnosed with motor neurone disease in 1963, at the age of 21, and given two years to live. He has been involved with the Association since the charity was started by volunteers back in 1979. In more recent years, in a formal role, as patron he has helped raise awareness of the disease, also known as ALS in the USA, globally. The association is indebted to Stephen for the many years of support and for the awareness he has raised of MND. He is a unique star amongst our VIP supporters, because of the length of time he has lived with MND but also because of his global profile and huge capacity to do good by getting involved with so many issues which affect our world today. We thank him warmly for his support and wish all the very best.” Brian Dickie, our director of research development, added: “The awful reality for most people is that MND is a rapidly progressing disease – it kills a third of people within a year and more than half within two years of diagnosis. “It’s impossible to say whether Professor Hawking holds any record for living with the disease but he is highly unusual. A small percentage of people live for more than a decade with MND, but to live with the disease for over five decades is exceptional.” Speaking about his disease in 2006, Prof Hawking said: “I have lived most of my life in the expectation of an early death, so time has always been precious to me. I have so much that I want to do. I hate wasting time.” The Association would also like to extend our best wishes to our patron, Eddie Redmayne, who celebrated his 35th birthday on 6 January.

Legal challenge on assisted dying: We note the recent news regarding the legal challenge on the right to an assisted death in the UK. Our thoughts are with Noel Conway and his family as they deal with the impacts of MND. The MND Association supports all people with MND, their families and carers in England, Wales and Northern Ireland and one of our goals is that everyone with MND achieves the highest quality of life possible and can die with dignity. In relation to assisted dying we remain neutral on this as we are a membership organisation and our members hold a wide range of views on this issue . If you want to read the Association’s full statement on assisted dying please follow this link <http://www.mndassociation.org/wp-content/uploads/mnd-association-policy-statement-on-assisted-dying.pdf>

New education bursary for health and social care professionals launches;

Association’s new education bursary for health and social care professionals is now open for applications – visit the education bursary page for the terms and conditions and more about how to apply. An educational needs survey carried out last year highlighted cost as one of the barriers which prevents professionals from taking part in training and continuing professional development activities. The education bursary seeks to address the gap by offering professionals grants to support educational activity that ultimately improves care, quality of life and clinical outcomes for people affected by MND. Professionals can apply for up to £250 in a 12 month rolling period. It is hoped that the bursary scheme will encourage sharing of best practice and an evaluation is planned in due course. Other charities offering a similar bursary scheme (Hospice UK and Prostate Cancer UK) report positive outcomes.

A mention in the New Years Honours List: Downpatrick resident Michael Holden, 45, who is living with MND, has been recognised for his ‘services to people with disabilities’ by being named a Member of the Order of the British Empire (MBE). Michael, who lives with his wife Jennifer and two children Georgia and Noah, was diagnosed with the neurological disease in December 2010. He overcame the shock of his diagnosis to set up a travel review site for disabled people, www.trip-ability.com. The website is dedicated to sharing experiences of travel, entertainment and products with the disabled community around the world and also provides employment for the disabled. Michael said: “My greatest achievement to date without a doubt is my continued battle against MND and surviving each day with renewed energy with the help of my friends and family, and most importantly with God given strength, for which I give thanks daily. When I was first diagnosed with MND, I didn’t want to meet anyone else with the condition but over the years I have met people through the MND Association and I have found it helpful.”

If you can get online then follow this link for many more interesting news items
<http://www.mndassociation.org/news-and-events/latest-news/>

Stop Press have a look at page 29 of Thumbprint!!

Association Launches New Five Year Strategy

The Association has announced strategic goals to represent the five year plan starting in 2017. These have been developed and refined alongside people with MND, trustees, volunteers, health and social care professionals, the research community, our members and staff.

Goal 1: Advancing research

We will be a leading international contributor in identifying the causes of MND and understanding how it progresses. We will support the research community in turning this new knowledge into potential treatments and ultimately a cure.

Goal 2: Ensuring quality health and care

We will do all we can to ensure that people with MND, their carers and families can access the care, support and information they need, when and where they need it, reflecting their diverse needs.

Goal 3: Strengthening professionals' ability to treat and care for people affected by MND

We will better understand the disease and clinical progression of MND. We will facilitate the sharing of knowledge, data and resources to improve outcomes relating to people's diagnosis, prognosis and treatment.

Goal 4: Working together

We will achieve more for people with MND, their carers and families by working in partnership and collaboration with other organisations, and by being a credible and effective operator in the external environment.

Goal 5: Raising awareness

We will increase awareness and understanding of MND and raise the profile of the work of the Association to influence decision-makers and reduce the social isolation so often experienced by people with MND.

Goal 6: The difference we make

We will continue to affirm our place as the leading authority on MND by growing the MND community – that is, all those who share our vision – and continually improving how we run our organisation.

For the full strategy please follow this link

<http://www.mndassociation.org/wp-content/uploads/MND-Association-Strategy.pdf>

The New York Group

No, not the Big Apple! We are pleased to let you know that after extensive work to ensure that people in the York area living with, or affected by MND receive quality care, York has a new Group.

For years a separate charity, "York against MND", provided excellent care and support to people in the area, particularly the provision of the York MND Specialist Nurse, Doreen Foster. It was therefore a significant challenge when this charity announced that it was having to close and this put into jeopardy Doreen's position. As a matter of urgency the Association worked with Doreen, the Vale of York Clinical Commissioning Group and Neurology Managers at York Hospital to secure statutory funding for the Specialist Nurse post. Fortuitously at this time the CCG were undertaking a review of Neurology Services across all conditions and so we were helped by this project working with Parkinsons UK and the Multiple Sclerosis Society. The end result was thankfully that the CCG agreed to pick up the funding.

The Regional Conference was held in York in 2015 which coincided with a focus on more localised support and meetings were established on the 3rd Thursday of each month. From this humble start the Group began and it is hoped it will continue to grow – a Charter has recently been signed!

The Association has also been fortunate to recruit a new Association Visitor, Val Corder, who is able to visit people in their own homes. Val has personal experience of MND and can provide particular support to those in a caring role.

Yorkshire Dales Branch will continue to provide some support for the first few months but we are very excited at this new development.

Winners of recent 200 Club draws

Recent winners include: October 2016 – Catherine Shuler
 November 2016 – Mark Craven
 December 2016 – Michael Wake

Dates for Your Diary

The next **Social Lunches** will take place at The Old Spring Well, Skipton Road, on the following dates
15th February 2017
10th May 2017

The **Branch AGM** will be held at 2 pm on Sunday 19th March 2017 at Pannal Village Hall

We are planning a repeat of last year's successful **Swing into Spring** so get the date into your diary **25th March 2017**

And of course on the **first Tuesday** in the month are the monthly get-togethers at Christian's Cafe in Crimple Hall on Leeds Road, Pannal (2pm – 4pm).

The usual jolly gathering for the Christmas Lunch was held on 14th December 2016 at Millstones Restaurant just outside Harrogate. They have very generously donated the proceeds from their raffle in the great sum of £145. Here is a picture of Libby (on the left) receiving the cheque from Jane Libby of Millstones to whom we send enormous thanks as they did exactly the same in 2015!



Branch Website and other Information

Please let us know if you would like to publish something on either our facebook page <https://www.facebook.com/MNDYorkshiredales> or our website www.mndyorkshiredales.co.uk .

Or perhaps you might like to contribute to Chatter? We would be delighted to publish items from Members in the next edition, just send your article to Ruth Pridmore (if you don't have email then give her a ring and she will let you have her address).

Can you help us save money by sending you paperwork by email instead of the Royal Mail? If you have an email address just let Ruth know and she will add it to the database.

Branch Contacts

Chairman, Peter Thompson – 01423 870130 chair@mndyorkshiredales.co.uk
Secretary, Ruth Pridmore – 01423 530764 secretary@mndyorkshiredales.co.uk
Treasurer, Geoff Catley - 01423 870143 treasurer@mndyorkshiredales.co.uk
Branch Contact, Margaret Thompson – 01423 870130 margaret.thompson730@ntlworld.com

National Contact Information

www.mndassociation.org

MND Connect – 0808 8026262

(note that the number for MND Connect has recently been updated)