

MESSAGE FROM YOUR CHAIRMAN



Your committee members are, as I write, somewhat exhausted from two very recent events which are featured later on in this edition. Firstly we welcomed Dr Tennore Ramesh from SITraN to our AGM who gave a lengthy talk on progress with his zebra fish project. We were struck by the enthusiasm Ramesh brought not only to his subject matter but also to the small strides that had been made with the use of zebra fish as the means of his research but also the thoughts of what progress might be made over the next few years. We await to hear of his findings with bated breath!

The second event was our annual Swing into Spring in Pannal village hall which was again attended by around seventy members and friends who enjoyed an evening of music, quizzes, chat and some very fine fish and chips. Several photos have been included later and, if the generosity of our guests was anything to go by, a very good time was had by all. And as a final surprise, we learned that the village hall management had nominated MND as the beneficial charity for their October quiz evening. We'll keep you posted!

Peter Thompson

WINNERS OF RECENT 100 CLUB DRAWS

Recent winners include:

February 2019 – Paul Bradley

March 2019 – Adryenne Hope

It is now time to renew your membership for 2019!
Enrolment forms are enclosed with this newsletter
(or sent by email with this newsletter).

Please join in. The odds for a win are extremely good.



FUNDRAISING NEWS

We know we are due a cheque for £253 from Waitrose Harrogate as we were in their Green token scheme in January - but we don't actually have the cheque yet!

We must also say thank you to those who are buying tickets in the Local Lotto as we have so far received £64.50 from this!

If you would like to join in then have a look at the website which is <https://www.thelocalotto.co.uk/support/motor-neurone-disease-association>

The Branch Management Committee is meeting up in the near future to brainstorm fundraising ideas (ideally as social events) so if anyone has any ideas please let us know.

THE LOCAL LOTTO
supporting **mnda**
motor neurone disease association

WE'VE LAUNCHED OUR LOTTERY PAGE

Buy Your Tickets From Our Page - We Get 50%

- We now have a THE LOCAL LOTTO page!
- Support local causes and win prizes of up to £25,000!
- 50% of all tickets sold from our page go to us!
- PLUS 10% goes to other local good causes!
- Tickets only cost £1 per week!
- Support us and win prizes - WIN WIN!

To Start Supporting, Visit www.thelocalotto.co.uk
And Search For: Motor Neurone

Supporters must be 16 years of age or older.

A FEW SNIPPETS FROM THE NATIONAL WEBSITE

Boldly stepping into the future - The Association took a step into the future at the launch of the Next Generation Think Tank, a project aimed at exploring, designing and developing technology to support people living with a range of neurological conditions and disabilities. Involving technical experts from a wide range of global companies, it is the brain child of Dr Peter Scott-Morgan, an Association trustee, Stuart Moss an innovation strategist at Rolls Royce and the Association's director of care improvement Nick Goldup who said: "The Think Tank is an incredibly exciting project which in a very short space of time has already brought together some of the most forward-thinking, innovative and creative companies in the world to focus on making life better for millions, and perhaps billions, of people. Dr Peter Scott-Morgan, who is living with motor neurone disease, has a vision for how he wants to live once the disease robs him of his ability to move, speak, eat and breathe. Using medical intervention to keep his body functioning Peter plans to use technology to provide him with a high-tech quality of life. The Think Tank brings together companies and people with the expertise and capability to turn his vision into a reality. And the benefits of this work globally shouldn't be under-estimated. There are billions of people across the world who are paralysed, disabled, 'locked in', living with neurological and degenerative conditions. Some of the innovations being discussed at the inaugural meeting of the Think Tank could give those people access to new experiences, opportunities and ways of living. The buzz in the room at the meeting was incredible and everyone involved is looking forward to where this meeting of minds will take us." The Think Tank has already attracted news headlines with BBC and Channel 4 cameras filming at the inaugural meeting held at the Rolls Royce Innovation Centre.

Carers Week - Following the success of last year's activities, the Association is proud to once again be supporting Carers Week. The theme this year is 'Getting carers connected' whether that be to financial support, practical support, via technology or to friends, family and the wider community. Carers Week aims to: (i) raise the profile of the role of caring and help the public identify themselves as carers and access support, advice and information; (ii) recognise and celebrate the contribution which the UK's 6.5 million carers make to the people they care for and their communities; (iii) highlight the challenges of caring, working towards better services and support for carers and the people they care for; (iv) bring together those organisations involved with carers, creating a shared presence and broad platform for caring issues within the national calendar. The Association is one of several partner organisations working together to represent carers on the national stage with the aim of influencing policy. We will meet MPs during Carers Week to talk about the challenges for carers and to ask them to support improvements and encourage positive change. The other important aspect of Carers Week is to engage and bring carers together locally within their community. The Carers Week Website (<https://www.carersweek.org/get-involved>) provides a directory where local groups and individuals can register events that they will run for carers during the week of 10-16 June to give them support, information or just a break and some fun.

Rugby legend doubles support for families living with MND - The Foundation set up by former Scotland rugby player Doddie Weir has doubled its donation to the Motor Neurone Disease Association to improve the lives of even more people affected by the terminal illness. Last July, a year on from the announcement of his motor neurone disease (MND) diagnosis, the former British and Irish Lion and Scottish international donated £100,000 raised through the My Name's Doddie Foundation to the MND Association. Doddie has now announced a further £100,000 contribution to the Association's grant scheme. This helps people living with MND to pay for adaptations to their homes and funds respite activities for carers, supporting much-needed pamper days or short breaks for instance. Doddie said: "One of our main aims is to help fellow sufferers of MND and families who, like me, are affected by this terrible disease and therefore we are delighted to be able to increase our funding to deliver that support. We recognise that the MND Association is best placed to distribute funds on our behalf and the grants have already made a difference to the lives of a great many people. We are only able to do this with the incredible support we receive from our fundraisers and we are all hugely grateful for their ongoing and committed efforts on our behalf." The MND Association's Care Grants programme totals more than £1 million annually. In 2018, the Association awarded grants to more than 1,800 people with MND, carers and young people affected by the disease. MND Association's Chief Executive Sally Light said: "We are so grateful for Doddie's continuing support of the MND Association and his determination to make life better for people like himself who have received this devastating diagnosis. This generous donation will make a real difference to people we support through our grant programme. For some people these grants are essential to allow them to make necessary changes to their homes so they can continue to live as independently as possible. For some the grant means a day out for the family or a treat for their carer. Whatever it is, it means so much."

AGM UPDATE

The AGM was well attended and after the business was over we had the pleasure of listening to Dr Tennore Ramesh from SITraN (Sheffield Institute for Translational Neuroscience) who gave us a fascinating illustrated talk about his research project to which we have contributed £37,000 thanks to our receiving in 2017 some very generous donations/legacies.



He explained that - as everyone present was well aware - MND (or ALS as it is known in the United States) is a very rare disease and it is therefore very difficult to get large pharmaceutical companies to research into these rare diseases, largely because there is no money to be made for them.

There is no known cause for the disease, 10% of cases are familial – meaning that there are some traits which can be traced in families but 90% are sporadic which makes any research far more complex. Therefore research has mainly been centered on the familial cases. Sadly 50% of sufferers die within 18 months of diagnosis, 20% within five years but 10% live for 10 years or more. This adds a further complexity to aspects of research. In fact research has shown that MND / ALS isn't just a simple disease at all but covers a wide spectrum with different causes and symptoms.

There are various causes but the most common seems to be linked to a gene C9orf72. Dr Tennore realised that Zebra fish can be beneficial to model MND as they can be observed from the earliest stage of development and thus used to study a single neuron resolution and study similar neural circuits that are affected in MND. It is also possible to perform both chemical and genetic screens on mutant zebra fish that exhibit the hallmark features of ALS / MND. He noted that a whole fish organism grows from an egg in just 24 hours.

One point of the research is to identify changes from drugs that will work for all variations. Using fish for research instead of mice means that screening is faster and cheaper and it is hoped that drugs that work in zebra fish and which are shown to be safe can then be used in tests with mice with a view to them being suitable for human use.

(Secretary's note: this only represents a brief resume of all the very interesting technical information detailed by Dr Tennore Ramesh. He is photographed with Branch Chairman Peter Thompson).

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? It would be lovely to publish something from one of our members - just send your article to Ruth Pridmore

Can you help us save money by sending your 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

GREAT FUN AT SWING INTO SPRING

A good crowd was entertained on 6th April with music by Spa Sax - who we thank greatly for donating their time for free. Everyone enjoyed a freshly cooked on site Fish and Chip supper and put their brains to work on the quizzes. We thank all those who attended for their generosity in support of the raffle etc and as a result funds have been raised for the on-going support of those MND sufferers in our area. Here are a few photos.



Overview



Spa Sax



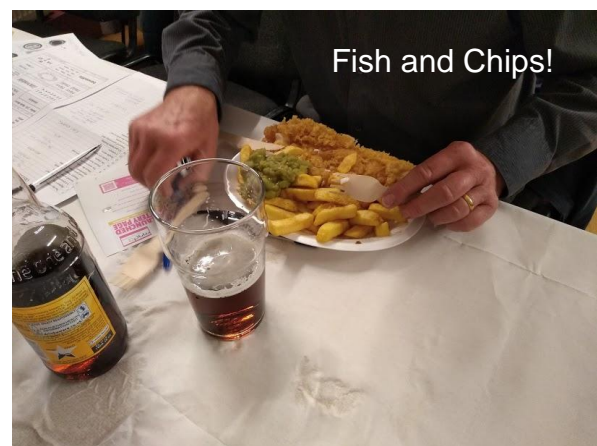
Just listening to the music



Quizzing



The queue – not too long!



Fish and Chips!

DATES FOR YOUR DIARY



On the **first Tuesday** in the month don't forget our monthly get-togethers (2pm – 4pm) which are held at **"The Barrows"** (previously known as Christians) in Crimple Hall on Leeds Road just outside Harrogate.

The next **Lunch** is planned for 22 May 2019 at Millstones